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Unschooling in general, and in particular in North Carolina, remains an undocumented educational homeschooling experience. The absence of homeschool and unschooling stories may close off the possibility of choosing those options to those who might otherwise seek an educational alternative to public or private schooling, especially for those families with children who experience disability.

I seek to articulate one experience of unschooling, so that the concept and available options can be better known and understood not only by parents seeking an alternative homeschool path, but by medical, educational, and service practitioners, and policy makers who might better serve families by knowing alternative schooling practices outside the context of compulsory public schools.

Adding stories of unschooling adds a theoretical tool to the schooling experience that could be used to teach pre-service teachers, educate administrators and policy makers, and inspire families to realize that there are alternatives to public and private schooling, and that there are alternatives under the often monolith term of homeschooling. In addition, I focus on unschooling as an alternative space for both the typical student and the student who experience disability.

In this dissertation I explore the unschooling experience by creating an autoethnography based on me and my immediate family's experience over the past nine years doing homeschooling as unschooling. This example of autoethnography explores life on the margins of schooling practices, the tensions between inclusion and exclusion,

access and equity, and the possibilities of unschooling as new space of liberation. The work uses critical theory and disability theory frameworks to inform its methodology and analysis.

HOLDING TIGHT TO THE TAIL OF A SHOOTING STAR:

AN AUTOETHNOGRAPHY OF UNSCHOOLING

AS JUST EDUCATION

by

William H. Purcell

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Approved by

_____
Committee Chair

APPROVAL PAGE

This dissertation written by William H. Purcell has been approved by the following committee of the Faculty of The Graduate School at The University of North Carolina at Greensboro.

Committee Chair_____
Carl Lashley

Committee Members_____
Leila Villaverde

_____
Jewell Cooper

_____
Elizabeth Chiseri-Strater

_____
Date of Acceptance by Committee

_____
Date of Final Oral Examination

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INTRODUCTION

The absence of homeschool and unschooling stories closes off the possibility of choosing these options to those who might seek an educational alternative to public or private schooling. My family is a good example. We were reluctant, and perhaps even hostile to the idea of homeschooling, before we found ourselves with nowhere else to turn. I hear a constant refrain from people I interact with about my homeschooling experiences, and the tunes are songs I used to sing before choosing to homeschool. Most responses from folks who really seem interested, but also reluctant, run along these lines: *We would love to homeschool, but…I wouldn't know where to start…I'm not qualified, am I?…We could never afford it.*

Most cite financial reasons for avoiding homeschooling. In addition, those who have children experiencing disability often state a lack of personal qualifications for providing instruction to their children as a reason not to choose homeschooling. Most say they simply *can't picture how it would work*. This autoethnography about unschooling provides one account of one family's experiences, which could open a path not for a duplication of our experience, but perhaps an inspiration to other families to forge ahead on their own unschooled journeys.

My family had a similar experience having read Hern's (1996) collection of unschooling/deschooling autoethnographic stories prior to exiting public school. The

accounts in Hern's work not only provided inspiration, but pragmatic ideas to enact our own unique unschooling journey. I hope this research can have the same transformative effect on another family in the future.

I also seek to articulate the joys of the unschooling experience so that the experience can be better known and understood by medical, educational, and service practitioners, and also policy makers. Adding stories of unschooling adds a theoretical tool to the schooling experience that could be used to teach pre-service teachers, educate administrators and policy makers, and inspire families to realize that there are alternatives to the dominant ideology that public or private schooling are the only choices. The absence of homeschool and unschooling stories may close off the possibility of choosing those options to those who might otherwise seek an educational alternative to public or private schooling. In addition, I focus on how unschooling can be an alternative for both the typical student and the student who experiences disability.

In this research I explore the unschooling experience by creating an autoethnography based on my and my immediate family's experience over the past nine years doing homeschooling as unschooling. In addition, the research covers five years of our public schooling experience with our children. This autoethnography explores life on the margins of schooling practices, the tensions between inclusion and exclusion, access and equity, and the possibilities of unschooling as new space of liberation. The work uses critical theory and disability theory

Research Problem

Many stories of homeschooling remain closeted. In particular, stories of a homeschooling niche called unschooling, remain deeply closeted. Despite record growth in the number of families opting to homeschool children in North Carolina (N.C. Division of Non-Public Education, 2019), few accounts of those experiences exist. Stories of families with children experiencing disability in a homeschool or unschooled setting remain virtually nonexistent. The stories that do exist circulate mostly among those who already practice homeschooling, rather than the world at large, leaving the public with few first-hand accounts of the homeschooling experience and in particular the unschooling experience.

Popular media fills that informational void by constructing homeschooling narratives of socially awkward and reclusive, religious fanatics (Hauseman, 2011). News media sensationalizes isolated cases of free-range parenting (Pimentel, 2012). The resulting narrative of a one-dimensional dichotomy of the homeschool family leaves public perception often at one end or the other of a scale from Jesus-freak to lazy Hippie. These flat characterizations help fuel fears of rejection, regulation, and intervention in homeschool and unschooled families, and that fear drives a reluctance to share educational practices outside of tightly knit social circles of like-minded families. I want to articulate one version of homeschooling, and in particular unschooling, not as an exemplar or blueprint, but as an inspiration to other families to create their own unique homeschool and unschooling stories. In this, I focus also on unschooling with a child that experiences disability. I seek to articulate one experience of unschooling, so that the

concept and available options can be better known and understood not only by parents seeking an alternative homeschool path, but by medical, educational, and service practitioners, and policy makers who might better serve families by knowing alternative schooling practices.

Question

When teaching research methods to undergraduates, I ask them to start with a hunch based on an interest. I do this because many students seem stymied by the prospect of picking one research topic from a complex world full of so many research possibilities. To help overcome this initial impasse, I'll have the students brainstorm a quick list of personal interests followed by adding in hunches about each one. Students will then pick one hunch to free write about, then share in pairs, and finally report out to the class. When I ask my students to define *hunch*, typical answers involve the words guess, feeling, and intuition. I counter with defining hunch as a verb meaning to push or nudge. Both the noun and verb definition of hunch seem apropos to starting the act of what researchers do, an act Kincheloe (2008) describes throughout his book *Knowledge and Critical Pedagogy* aptly as *knowledge work*. With a hunch in hand, students hunch forward toward the act of research.

I believe knowledge work/research should start with a personal interest in the subject, not only because I practice interest-based pedagogy, but because too often research in the academy, as well as teaching about research, becomes a cold, impersonal act devoid of relation. As I teach research to undergraduates, I start with the idea that all research is fundamentally about human beings, thus a relational act as Freire (2000)

describes of "hopeful inquiry human beings pursue in the world, with the world, and with each other" (p. 72). Interests, guesses, feelings, and intuitions all become the initial human drivers toward pushing or nudging researchers into knowledge work that starts as what Freire labels a *hopeful inquiry*. Why hopeful? Like hunch, hope is a feeling, an intuition, and a guess, but with a connotation of optimism. I believe all research should start positioned as a hopeful inquiry into transforming the world because hope is the human relation that makes the knowledge work important and worth researching. If a researcher's knowledge work doesn't move toward hope, why should other scholars care, why should the researcher care, why should the researched care? Most of my students want to begin with describing what to research. The pedagogy I describe aims to help the student researcher articulate why they are researching, which I think is the most important place to start because the answer frames everything that comes after. I ask my students to take their hunch and develop it into a statement of hopeful inquiry that becomes the answer to why research this idea?

I ask the same questions of myself as I research. While my list of interests is long, I've narrowed the list to three core personal interests: *communication* because of a 30-year history in the field as a practitioner and nearly half that as a scholar; *unschooling* because it describes what my family attempts as homeschoolers and because unschooling influences my pedagogy as a professor; and *disability* because of intimate personal relations to the experience of it through self and family. I'm long past developing these interests into hunches, but I will briefly look back to recover what drove me toward my dissertation topic. My hunch about communication is that more attention should be given

to metacommunication, or communication about how we communicate, during the research act so that researchers seem less elite, more connected to the world, and so that knowledge work is open and accessible to more people. My hunch about education is that many of the criticisms of public schooling over the past decade are about to be repeated in undergraduate education over the next decade. An example would be curriculum decisions in public schooling being taken out of the hands of classrooms teachers turning them into robotic delivery automatons of pre-packaged, commodified pedagogy created by corporations, that this process will be repeated in undergraduate education as low-wage adjuncts become the online delivery vehicles for curriculum created by a handful of tenure-track faculty or purchased from corporations. My hunch about unschooling is that if more people knew about it more people would choose it. My hunch about disability is that as more voices rise articulating the experience of disability as cultural, beautiful, and natural, that society's harmful attitudes and actions will diminish. Hunches based on my personal interests. Now to do what I ask of my students — to develop these into a statement of hopeful inquiry that becomes the push, the nudge, the hunch forward into research. I am often just like some of my students. I bite off more than I can chew. I try to pack too much into one research project. I try to tackle too many hunches and have too many research questions. Narrowing my focus to one essential research question was both difficult and important. Simply put, my research question is: *What is the story of one family's unschooling experience, in particular unschooling with a child who experiences disability?*

But how did I come to this question a foci for my research work? Selecting frameworks for research during the opening years of the second decade of the new millennium might seem an easy task. Has easier access to a more vast array of theoretical and methodological choices ever existed, especially for the interdisciplinary scholar? Increasing specialization of scholarly fields, subfields, and journals supporting those new fields, and open electronic access for those with the privilege of free access to the seemingly exponentially-increasing bodies of knowledge supporting those fields, all fuel the digital information age and its billowing data clouds that seem to completely envelop the contemporary scholar. Information drenches the researcher who stands in a field of study, simultaneously feeding the growing nebulosity of new academic expressions of knowledge and attempting to navigate the very fog the scholar helps sustain. This is my milieu. I'm standing on shifting ground, the fields around me blurring as I cross borders and attempt to locate and describe my scholarly body, a body that refuses to stand still, a body swimming in the ever-changing bodies of knowledge. I attempt to locate myself so that I can be known to others, so that I can raise my own voice through creating knowledge.

From the start, I want to acknowledge my reluctance to state a *thesis* to *prove* because the very notion is antithetical to my axiological stance as a researcher in the qualitative paradigm and my personal epistemological understanding of valid research, as well as my ontological view of the role of researcher. I contest the notion that a provable theory is anything but another hegemonic tool to force scholars outside the so-called neutral and objective traditional academy to capitulate to patriarchal notions of what is

valid knowledge construction. As a scholar, my aim is to unveil power in knowledge construction, not to reify it by suggesting it is possible to articulate a provable theory. I believe this effort is true to critical aims to explore power, discourse, hegemony, identity and intersectionality. And perhaps, by combining the metaphor of a crossroads described by critical cultural scholars Nakayama and Halualani (2010) and the metaphor of a bridge described by Mendoza (2010), I would suggest a turning off of, or out of, the crossroad by taking a bridge, into an unexplored field off the cold, hard institutional pavement to a place beyond the shadow of the ivory tower, a new space where the imagination of what is truly possible through critical qualitative research and interdisciplinary knowledge-work can take shape in a postmodern turn, not into nihilism or relativism, but into the fluid, open, rigorous, and liberating space, where there is no institutional need to oblige the typical positivist aims of the academy, but to instead, explore new ways of epistemological construction.

Part of this new way of seeing and doing research is moving away from the idea of a research question to the idea of a research opportunity. My research act in the critical tradition becomes finding a research opportunity and entering into a relationship with the subjects or objects involved in that opportunity. Ontologically, my story is always a part of the research because my historical, social, political, economic, cultural, and ideological situation impacts the research in ways that need to be articulated in order to unveil as much as possible that which produces and constrains my research. I do not value a predetermined truth for which I prescribe a predetermined research path toward proving or disproving. Instead I value the process of research that unveils the construction of the

research act so that the academic product transcends the traditional taxonomy and discourse of foundations, categories, and so-called valid and reliable truth claims in favor of an honest, open exploration, and articulation of the complicated, chaotic, and ever-changing worlds we enter as researchers. If I start with a question, that question is a point of departure, not an anchor. The goal is always movement toward social justice and the research act should not tether the researcher to the static moorings of what traditional research says *is*, but instead be a launching pad into the critical notion of what *could be* or even the political notion of what *should be*.

Limitations and Further Research

Privileging of text is both a limitation of this research and an area for further exploration. Though this dissertation is based in written words, I see future research that explores these same ideas in multiple interpretive modes. Scholars embracing qualitative inquiry should move beyond the linear pages of the academic journal, and into the growing field of performance (Denzin, 2003) whether photography, play, dance, rap, video, song, or flash mob, or any of the endless opportunities offered beyond the traditional academic paper. Jackson (1989; as cited in Conquergood, 1991, p. 188) refers to the privileging of written text by the academy as "the textual bias of Western civilization." Halualani and Nakayama (2010) echo this call to get beyond the page asking for, "more attempts to make visible (in published, online, performative forms and demos) the full cycle of…political projects" (p. 5).

Beyond how the research is presented, many possibilities remain for further research including research in various settings, examples of, and criticisms of the

unschooling experience. Through my work researching unschooling, I provide one example of one way of not only doing unschooling, but of creating an autoethnography. To be clear, I don't want to insist this is the only way or to suggest a universal blue-print, but only to add my voice through my example to what is possible through research within the theoretical frame. This could be cited as a limitation of the study in that it does not represent more than one perspective. However, I believe I've made it clear that what traditional scholars might call a limitation, qualitative scholars call a strength.

However, I do see possibilities to work with other scholars in the future to bind multiple stories together into one volume that might speak to the autoethnographic experience or to unschooling, much like Hern's (1996) *Deschooling Our Lives* that combines the work of 25 researchers/writers into one book about the deschooling experience. The variety of authors, experiences, contrasts, and juxtapositions provides not a monolithic picture of deschooling, but a more textured, quilt-like representation. The same applies to research in unschooling. Certainly, more research about unschooling is needed. More stories need to be told. The same is true for the experience of disability.

Why Autoethnography?

While a full-time graduate student at The University of North Carolina at Greensboro and a full-time lecturer at Appalachian State University, I sought to incorporate the theories, methodologies, and research I studied in graduate school into my undergraduate classrooms. In particular, autoethnography intrigued me as a scholar.

It's tough enough to teach traditional research methods to undergraduate students, much less newer qualitative methodologies with a shorter history, yet, the extra effort to

teach autoethnography was well worth it, because students in my classes craved alternatives to traditional quantitative methodologies, craved alternatives in creative expression, and craved pragmatic paths toward social justice transformation. Autoethnography offered an opportunity to satiate these cravings by allowing students to explore the creation of knowledge through more creative means than most traditional undergraduate research projects in my department and perhaps, throughout our university. In my classes, students created expressions of knowledge through autoethnographic narrative. I observed that students thrived in open spaces for creation, but struggled to connect those creations to theory in a way that was understandable to others. Students easily composed autoethnographic narratives, but struggled to identify and connect their own histories to the production of their academic creations. Further, while students easily noted the social justice changes they desired, they struggled with articulating possible paths toward social justice change, leaving important unanswered questions at the end of each semester: *What now? What next? After this inspiring final project presentation by my peer, what can I do? How can I further the aims of social justice?*

These unanswered questions did not invalidate the knowledge work created by students, however it continually led me toward developing better ways of teaching. I sought a pedagogy that had the potential to unlock more long-lasting and transformative experiences for both knowledge creators and the audiences reached by those creations.

I've found that autoethnography provides a useful framework for teaching undergraduate students schooled by more than a decade of the testing requirements of No

Child Left Behind, who simultaneously feared and desired a new space for the exploration of knowledge. To ease the fear and support the desire for learning, I attempted to build a bridge into autoethnography and aimed to walk across it alongside students as a guide. I also wanted to help students create products that could be more understandable and useful for transformative social justice work.

Broadly, Denzin & Lincoln (2011) call qualitative researchers to create new spaces, new discourses, and new fields of inquiry where new forms of academic products flourish (p. ix) — I believe autoethnographic writing is one possible answer to this call. Denzin (2011) challenges a new generation of scholars to "articulate its epistemological, methodological, and ethical stance toward critical inquiry" (p. x) — I believe autoethnographic inquiry could be one example of doing this critical inquiry for a new generation.

Hope guides my work. I counter the contrast to typical research expectations with the idea of the researcher developing and holding onto a *hopeful optimism* in contrast to what cultural studies scholar Lauren Berlant (2011) named a *cruel optimism*. Berlant describes this optimism as one in which a person pursues freedom without realizing the very thing you pursue is preventing you from being free. I have felt Berlant's cruel optimism inside the academy where gatekeepers of the status quo work to keep knowledge construction in bounds of what is perceived as normal and expected. So by capitulating to the academic system's norms, I in effect stunt my flourishing and freedom by taking my place as a cog in a machine that cruelly allows the light of freedom to fall upon me without me ever being able to bask fully in its glory. A hopeful optimism, in

contrast, locates the freedom and flourishing not as an outside place one is trying to reach, but something inside the person. Though the system keeps you from fully flourishing, you can imagine a world in which all light can shine, so you strike and struggle against the machine, but at the same time allow others to see your light, so that more and more people bask in it, and join you to add their own light. What you create where you are becomes what you had hoped for in the first place. It's not an act of escape, but an act of creation. What *could be* becomes *what is*. This is perhaps a meta-purpose of my research, through an act of creation in developing autoethnography *what could be* becomes *what is* — and that mirrors the aims of social justice — that *what could be* becomes *what is*.

Situating the Research in Critical Theory

The tenets of critical theory are strong threads in a web that supports the nature of autoethnography as theory and method. It becomes a catch-22 to write about the tenets of critical theory, due to perhaps the only truly basic tenet of critical theory: that there exists no stable definition. Kincheloe, McLaren, and Steinberg (2011) warn of *packaging* various notions of critical theory, especially the divergent views of those scholars credited with the development of critical theory in the Frankfurt School, "critical theory should not be treated as a universal grammar of revolutionary thought objectified and reduced to discrete formulaic pronouncements or strategies" (p. 164). Critical theory involves an evolving criticality (Kincheloe & McLaren, 2008) which resists concrete foundations in favor of an ever-growing articulation that is responsive and searching for

new connections and new ways of understanding everyday life and human experience. Bronner's characterization of critical theory:

> Critical theory was intended as a general theory of society fueled by the desire for liberation. Its practitioners understood that new social conditions would give rise to new ideas and new problems for radical practice and that the character of the critical method would change along with the substance of emancipation. (Bronner, 2011, p. 24)

Kincheloe and McLaren echo Bronner who explain evolving criticality as *reconceptualized critical theory*, "critical theory is never static; it is always evolving, changing in light of both new theoretical insights and new problems and social circumstances" (p. 407). I will move from the word *tenet*, which implies a connotation of unchanging doctrinal truth, to the word *aspect*, which I use in addressing the tenets as aspects of critical theory.

In astrology, aspect becomes a description of a relation between one celestial body and another (aspect, 2012). In grammar, aspect becomes a linguistic expression of the relationship of an action to time. Similarly, aspect can refer to how any object is viewed or positioned, or both. Aspect also has other denotative meanings: referring to its singularity in the plural; its particular in the overall; the perception from a certain standpoint; one characteristic of many; or one quality of many. Most importantly, aspect can mean gaze or the act of looking at something. In each different definition, the word takes into consideration the position of the observer or the observed with the understanding that that position will change because the universe is always in motion. So too, critical theory is never stable because it takes into consideration the positions of the

observer and the observed. The universe is always in motion, so critical theory, by reflecting analysis onto itself, onto its researchers as well as what is researched, is always in a state of becoming, always temporal, and if pinned down by text, always done so to locate the theory and method, researcher and researched, in the historical, social, political, economic, cultural, and/or ideological aspects of the situation. Because of this emphasis on position, aspect becomes a better way to describe the *tenets* of critical theory. The aspects I describe are partial, changing, moving, relational, temporal, qualitative, and marked by my position as the person describing the aspect. With those qualifications, I can then begin to describe critical theory:

> Socrates called conventional wisdom into question. He subjected long-standing beliefs to rational scrutiny and speculated about concerns that projected beyond the existing order. What become know as critical theory was built upon this legacy…its most important representatives would wage an unrelenting assault on the exploitation, repression, and alienation embedded within Western civilization. (Bronner, 2011, p. 1)

A central aspect of critical theory is its contested nature. While most scholars ground the development of critical theory in the Frankfurt School or in the writings of Marx, Bronner traces the roots of critical theory much further into history. Whether one begins the discussion with the Frankfurt School or Marx or Plato, the grounding is always contested and that is what makes critical theory, well, critical theory — the contested nature. Bronner disrupts the traditional critical theory narrative which typically begins with the inception of the Frankfurt School in 1928. Instead, Bronner starts his book on critical theory with a story about Socrates. Could this disruption be furthered contested by

suggesting Eve as the original critical theorist? After all, whether you believe, as the bumper sticker states, *Eve was framed*, or that she committed the original sin, either way she was condemned for corrupting the morals of the time, for simply pursuing knowledge beyond the existing order of the garden of Eden. To me, Eve's lust for an encompassing complete knowledge was fulfilled with one bite and the ensuing realization that the garden of Eden was not reality, but a veil by the one in power to hide from the working class Adam and Eve the struggle to maintain the ultimate status quo. As a critical theorist, Eve sought liberation from *what was*, but envisioned *what could be*. Eve's praxis mirrors my own lust for an all-encompassing, universal knowledge, and the unveiled reality from a bite of the critical theory apple — that all knowledge is contested and will be for all time. What a cruel revelation! The only all-encompassing knowledge is that there is no all-encompassing knowledge. Yet, scholars still lust after and seek the unbitten apples, hoping to taste that which Eve proved long ago is not possible — that one knowable totality exists to explain it all.

The contested nature of even where to start a discussion on the origins of critical theory points to perhaps critical theory's only central aspect: knowledge is always contested. Phillips (2000) titled his book on critical theory *Contested Knowledge*. Contested knowledge becomes an apt phrase for summarizing critical theory. Contextualizing knowledge is what a scholar does with critical theory by articulating the various social, ideological, and historical locations of the researcher, researched, and research act. However, no matter how much contextualization is provided in the academic product, there will never be complete agreement on the validity or reliability of

the knowledge produced, nor will that knowledge stand for all time. So through the lens of critical theory, all knowledge is contested, even contextualized knowledge produced by critical theorists. Critical theory is as Phillips writes *contested knowledge*. Phillips describes the problem:

> Now try to imagine a discipline that is constantly in crisis, continually questioning its own basic premises. Critical Theory often seems to be in this state: continually in crisis, without faith in any founding frame of theoretical reference, constantly questioning its own or others' basic principles. (p. 33)

Critical theory becomes a phoenix burning out through turning its own lenses of analysis back on itself, yet inevitably rising again from the ashes. What sustains critical theory through this constant cycle of birth, death, and rebirth? Phillips highlights the seemingly unanswerable question by asking students of critical theory, "in the face of the bewildering plethora of conflicting points of view in the contemporary intellectual scene, is it possible ever to get a framework through which to understand it all?" (pp. 219-220). He answers *yes* and uses an analogy from his youth as a motorcycle messenger learning the complex streets of London:

> Critical Theory challenges the newcomer with a density of areas, names and alternative routes through it, in much the same way as a city does. That is partly because it does not specify its discipline and cannot afford to ignore developments in areas that might seem foreign. You may become interested in certain aspects of the subject, certain writers even, and remain detached and aloof from others, though all that could change at a moment's notice — a chance encounter with some obscure German philosopher after picking up an intriguing reference, perhaps….[a map might] tell you how to get there but making the knowledge your own will be your responsibility. (p. 220)

My journey into critical theory has been similar, with chance references in readings or database searches or comments on blogs leading me to scholar after scholar claiming to know critical theory, yet Phillips comes closest to capturing what others fail to say — that you can't capture it, and if you did, it wouldn't be the same the next time you looked at it because *you* are not the same and the world is not the same. Critical theory is constantly evolving just as the scholars that use it are also constantly evolving. There is no hope of nailing it down for it was never meant to be nailed to wood, but to be constantly questioning itself and constantly growing into something new, fulfilling the notion of evolving criticality. That said, at least Phillip's theoretical map of critical theory gives us a temporary frame to understand it, as long as the scholar understands the fallibility of maps as human constructions.

Kincheloe (2005) noted, "if what we designate as truth is relational and not certain, then what set of assumptions can we use to guide our activities as professionals, to inform our questions as cultural workers?" (McLaren, 1989; Pinar, 1994; Rasberry, 2001; cited in Kincheloe, p. 37). If the critical tradition is always changing and evolving, if it avoids too much specificity, if there is always room for disagreement, if there are no fixed characteristics, if there are no blueprints, then what are you left with?

Critical theory works to confront two forces: that which seeks to produce it; and that which seeks to constrain it. Kincheloe points to the problem of all inquiry, "inquiry and the knowledge it produces are never neutral but are constructed in specific ways that privilege particular logics and voices while silencing others." It might seem easy to voice the forces of production and constraint in a critical-theory infused research-process to

highlight the social, historical, economic, cultural, and ideological forces that shape knowledge production. However, as Kincheloe points out, in research, it is not possible or desirable to prevent privileging of certain voices and silencing of others.

Like a Swiss Army knife or duct tape, critical theory becomes one of the most versatile tools, with plural possibilities of its use only limited by the imagination and the contexts of the person wielding it. A Swiss Army knife can be used as a weapon, to pick a lock, or to pare an apple. Duct tape can be used to bind two objects together, to stop a leak, or even to create clothing. What matters is the intentionality of the person using the tool. There is no definition of critical theory, only aspects that describe its possible use. Once critical theory or the Swiss Army knife or the duct tape is methodologically employed in an unfolding act in the empirical world, one can write the text that tells the story of the knowledge created. Critical theory always leans toward action for social justice change, as Bronner (2011) notes:

> Critical theory must again, though in new ways and under new conditions, view itself as a theory of practice. It should offer practical ideas for dealing with exploitation and repression, and rely more strongly on the ethical traditions associated with humanism. (p. 74)

Look, here is how I peeled an apple. Look, here is how I made a duct-tape wallet. Look, here is how I constructed my research. It is not enough to create knowledge, even contested knowledge. How has this knowledge changed the world? An inscription on Marx' stone grave marker in London reads: "Philosophers have only interpreted the world. The point is to change it!" Did the apple alleviate hunger? Did the homemade

wallet undermine capitalism? Does academic product change the world? These are the central questions raised by the employment of critical theory through the act of research though certainly those questions are — as all knowledge is through the lens of critical theory — contested.

Disability Theory, Critical Disability Theory

Disability theory, like most theories that fall under a critical perspective, is always a contested site, changing through the contexts in which it is considered (Parekh, 2008). I want it to stay still and be knowable, but it is not, just like the disabled body that refuses to be defined (Snyder & Mitchell, 2001). In my research, I explored ideas, images, and experiences of disability in various contexts from public to private, from insider to outsider, from self to other. In this exploration, I used the defiant heart at the core of disability theory to fracture expected meanings, especially those made by positivists.

The positivists tell us that gravity is real, but still we try to defy gravity. That is what we do with disability theory — we interrupt, we disrupt, we rupture, we rip, we break, we fracture, we embrace the chaotic, the fluid and live in the cracks and stand on shaky fault-lines (Villaverde, 2010) and fight against the so-called solid ground that often elitist, patriarchal positivist researchers claim to stand upon as they try to force disabled bodies into neat little boxes.

Who are these researchers, wanting to help the disabled body into a proper box? Often scholars, students, and service providers in what I will broadly call Special Education Services (SES). These are the folks in the classrooms, on the ground, making policy, interacting with families, writing IEPs, doing the everyday work, often

paperwork, with and to people experiencing disability. I believe most are steeped in positivist theory and methods that value an objectivist ontology and a realist epistemology and they want to at all costs deny the existence of any axiology entering into their research. Watson, Roulstone, and Thomas (2012) echo this split between the special education as a field and disability theorists:

> Debates over methodological purity and ideology deflect from the essential epistemological fissure between traditional special education and disability studies in education. The former is founded upon understanding as a reflection of defective individual pathology. The response to such an assumption is that the task of the special educator is to diagnose the nature and severity of the pathological defect and then, armed with that knowledge, devise special interventions, placements, and programs for that child with special education needs. (p. 225)

The tension between these two views of disability is a space I explore in the research. Using critical disability theory as a framework, I take a political turn and stance. I am a critical scholar committed to social justice change. If the results of the research don't result in social justice change, then that research isn't valid. My validity resides in the change we make in the world. Hosking (2008) writes:

> Critical disability theory is intentionally political in that its objective is to support the transformation of society so that disabled people in all their diversity are equal participants and fully integrated into their communities. (p. 18)

I explored the political nature of disability as it relates to public schooling and the process of deschooling.

Language is a key component of both disability and critical disability theory. *Severe disability* is one label those in SES communities use to mark disabled bodies and minds. *Normal* is another, though not applied to the disabled body, but used as a contrast. Hosking (2008) writes:

> Language is popularly assumed to be a transparent, neutral means of communication. Critical theory, however, understands language to be inherently political. Language carries with it ideological implications which are more or less transparent. The word disability is used to identify a sub-set of a population but the fuzzy boundaries which occur with all social categories are nowhere more contested than with disability. (p. 14)

Disability theory questions language, such as *severely disabled,* and turns the focus on one's humanity. Watson, Roulstone, and Thomas (2012) note, "[a] special education need is seen a euphemism for the inability or unwillingness of schools to education all children" (p. 225). My research examined not only language, but questioned assumptions of purpose made by special educators in public school settings. Disability theory focuses not only on language, but agency and advocacy in response to the medical model of disability. Siebers (2008) describes the medical model:

> The medical model defines disability as a property of the individual body that requires medical intervention. The medical model has a biological orientation, focusing almost exclusively on disability as embodiment. The social model opposes the medical model by defining disability relative to the social and built environment, arguing that disabling environments produce disability in bodies and require interventions at the level of social justice. (p. 25)

Disability theory and the social model asks where are you locating the disability? Do you locate it in the person? Is a person disabled? Does the disability reside in the

person, severely? The answer is no. Disability resides in the system. A person who uses a mobility (wheel) chair is not disabled, the disability is not in her legs, her body, or her DNA. The disability is in the building with no ramp. The disability is in the room with narrow doors. The disability is in the temporarily-able bodied people who force her to accept a label to get an accommodation. The disability is not inside the person, but in the social constructions society creates that oppress the person who experiences disability.

No body is disabled. We experience disability. Disability does not reside within us. The word disability can be pejorative. It's a term used to divide society into those who wield power and those who don't. Goodfellow (2012) writes about disability theory and in particular the power of language in regard to labeling, both from special education service providers and peers who use it pejoratively to disempower:

> Pejorative disability labels — such as retard or goof and DD [developmentally disabled] — reinforce the social dichotomy between the able and disabled have momentous ramifications upon the embodiments as persons learning and living with disability. (p. 79)

Disability theory focuses on our language and our discourse. SES schools teachers into accepting a disempowering language that reifies normalcy. There is no normal except that which keeps the status quo in place. The language of SES works to keep those with so-called *severe disabilities* hidden away in their own schools, in their own classrooms, with their own teachers, with their own bathrooms, with their own tables in the cafeteria, with their own peers, with their own *special curriculum*. Disability theory asks us to question these practices and tear down those walls, shred the folders, and end

the labels. Through the lens of disability theory all students belong together under one roof, in one classroom, on one bus, with one teacher. Yet, SES continues to segregate students experiencing disability.

Disability theory is about power and powerlessness (Siebers, 2008). Does what workers in SES are taught work to empower their students or just control them, or just prepare those students for the job that awaits them in food or filth? Students experiencing developmental disability, if they are lucky enough to find work (Jennings, 2017), can look forward to a life of work jobs centered around food or custodial services. Disability theory would challenge researchers to ask are functional curriculums just training students as food and filth workers? Could they aspire to something more? Why not the arts? Why not anything else? Because students experiencing disability don't fit the *normal* standard of the able-body majority, and they are forced in roles of service or relegated to the margins of society. So disability theory would offer critique of a functional curriculum and ask why not teach agency, advocacy, resistance?

Disability theory is about radically re-imagining the very meaning of disability. Disability theory embraces contradiction, polysemy, multiplicity, complexity and chaos. Disability theory asks us to stop seeing those who experience disability as the *other*, as *abnormal*, as something to be cured, prevented, or rehabilitated. Can you imagine disability as beautiful? When you see a person who experiences disability, can you imagine them as beautiful? Disability is beautiful (Anderson, 2015; Purcell, 2008).

Disability theory is about social justice change (Mladenov, 2016). It would ask what are you doing in your life that ruptures the status quo? I believe this

autoethnography of deschooling from compulsory public schools into homeschooling can be a rupture for those with the open mind and imagination to envision a new way of being in the world.

CHAPTER II

LITERATURE REVIEW

> Why do so many people -- even ardent critics of schooling -- become addicted to education, as to a drug?
> — Ivan Illich, 1996, *Deschooling Our Lives*, p. viii

> After an adult lifetime spent teaching school, I believe the *method* of mass schooling is its only real content. Don't be fooled into thinking that good curriculum or good equipment or good teachers are the critical determinants of your son's or daughter's education.
> — John Taylor Gatto 1991, *in an acceptance speech for New York State's Teacher of the Year*, p. 19

Deschooling Starts

Understanding the literature about deschooling, homeschooling, and unschooling begins with Roman Catholic priest turned philosopher Ivan Illich whose 1971 book *Deschooling Society* launched both interest in and debate over the concept of a world not devoid of schools, but free from mandatory, publicly-funded schools that commodified learning into a scarce resource (Hern 1996, 2008; Illich, 1996, 2006). Illich critiqued most of the institutions of modern Western culture from education to energy production to transportation to medicine to work itself. However, he is perhaps most known for his theories about education, and I would argue, least know for one of his most important contributions to education, one that I will detail later in this chapter, the formation of the Centro Intercultural de Documentacíon where some of the most influential educational

thinkers of the 20th century gathered to write, discuss, and debate, and where Illich wrote his landmark book.

In *Deschooling Society*, Illich (1971) envisioned a utopian open society of leisure where citizens viewed the substance of learning as simply the process of everyday living where people freely shared knowledge making it so abundant that there would be no need to compete over any type of resources thereby saving both society at large and the planet from eminent destruction by a rampant, self-serving consumerism. Consumerism when coupled with compulsory education schooled the public into a lifetime of bonded service to the existing power structures of the day leaving society and its members enslaved and dependent on the very system that schooled them into believing that the substance of education was located in the very processes that, in reality, enslaved them (Illich, 1971, 1996, 2005). For Illich, there is no difference in learning and living everyday life and therefore no need for special institutions like schools to teach and no need for special vocations like educator. Instead anyone can and should teach anyone else as they simply go about their everyday life simply living (Hern 1996, 2008; Illich, 1996, 2006). Today, many of those seeking to deschool their own lives through homeschooling or unschooling mirror Illich's reasoning, whether they realize it or not.

In the 1970s after *Deschooling Society* appeared, the term deschooling was generally accepted as the idea of removing schools from society at large, especially compulsory schools (Illich, 1996; Routray, 2012), even though Illich writes in 1996 that this interpretation was in fact a misinterpretation due mostly to the president of Harper Publishing who wrote the book title without consulting Illich (p. vii). Illich would have

preferred the term "disestablishing," which has a connotation of separation, as in separation of church and state, rather than elimination (p. vii-ix). For all of Illich's utopian musings on a society without schools, he sometimes left the theoretical realm and provided pragmatic ideas for a re-envisioned world. When I first read Illich's ideas, one of my first questions became: if we were to follow Illich's dream of eliminating schools, then what happens to the physical buildings? Illich (1971) addressed this and other pragmatic issues around his utopian vision, by suggesting a repurposing of school buildings into public spaces where citizens could meet to seek out learning experiences, describing these new spaces as webs of connection where learning happened freely between consenting individuals. In his book *Instead of Education*, John Holt (1976) built on these ideas from Illich and many of them are today used by homeschoolers, as detailed by Farenga (2004):

> Eschewing school schedules for personal schedules; enrolling in independent study programs; taking individual courses at different schools and community colleges; using community resources such as pools and playgrounds for meetings and group play; attending learning centers, museums, concerts, lecture series at colleges and libraries; and creating new local resources, such as learning exchanges and local environmental protection groups. (p. x)

Even though he conceded this type of schooling might involve exchange of money or the bartering of services, the difference lies in choice. Illich (1971) writes, "to deschool means to abolish the power of one person to oblige another person to attend a meeting" (p. 94). Illich (1971) suggested a society frustrated with the state of compulsory public schools simply lacked the imagination and "appropriate language" (p. 73) to

"visualize either a deschooled society or educational institutions in a society which has disestablished school" (p. 73). That statement rings true today in regard to language, nearly 50 years later, as the term deschooling, much like homeschooling and unschooling, remains contested with multiple meanings in various contexts (Rolstad & Kesson, 2013) making straightforward dictionary definitions difficult. However, I believe the imagination Illich saw lacking then, has arrived today in the spirt and activity of the vast array of families choosing to deschool into homeschooling situations in hundreds of varieties, many of them also falling under the smaller umbrella term unschooling.

Defining Deschooling, Homeschooling, Unschooling

Illich's *Deschooling Society* launched the word deschooling into educational discourse. However, it would take a decade more for the terms homeschooling and unschooling to enter educational lexicon (Farenga, 1999), so defining deschooling seems an appropriate place to begin. One camp of dictionary definitions of deschooling resembles this one from Dictionary.com which focuses on Illich's ideas:

> To abolish or phase out traditional schools from, so as to replace them with alternative methods and forms of education, or to separate education from the institution of school and operate through the pupil's life experience as opposed to a set curriculum. (Collins English Dictionary, 2012)

The other camp of dictionary definitions pulls form a more contemporary view of deschooling that has come to denote both the process of taking children out of public schools to be homeschooled and the time period of that process from the first decision to exit through the adjustment period to homeschooling (McGrath, 2010). For example, "the

process of adjusting to the non-school environment of everyday life after leaving the education system" (In YourDictionary, n.d.). McGrath's definition goes beyond simply adjusting to the new life outside public schooling to describe deschooling as a time "during which we unlearn our previously held concepts about learning and raising children" (2010, p. 26). Families leaving public schooling often are in need of a new vocabulary to relate the process to others who might not understand or have not encountered the concept prior, and yet homeschooling doesn't seem to fit, so we have deschooling. One might say, "we are going to deschool next year," meaning your family will exit public education. One might also say, "we're still deschooling, but we're close to figuring it out." Both definitions give those new to the term deschooling a solid ground to understand the word's origins as a theory and its everyday use today to describe the process of exiting public school into something else. Yet, both camps fail to capture the critical nature of deschooling.

Geraldine and Gus Lyn-Piluso (2008) capture the critical spirit of deschooling that I believe Illich intended and that my family seeks to emulate in our own deschooling, homeschooling, and unschooling journey:

> Deschooling does not simply move the school to home—it rejects the school and its authoritarian nature completely. It aims at the full development of human beings who 'own' themselves, who are critically conscious, free individuals committed to social justice transformation…(requiring) a conscious effort to de-professionalize learning by acknowledging it as a lifelong, cooperative project of questioning and discovery, thinking and rethinking…parenting, in the deschooling family, becomes a revolutionary activity. (p. 84)

Deschooling in this context becomes becomes a radical rejection of schooling and a mutual endeavor between children and parents/caregivers that challenges the traditional notions of authority in favor of egalitarian relations and dialogue as the family unit goes through everyday living. Many folks interchange the word deschooling with homeschooling, however the Lyn-Pilusos caution against this by further offering an explanation of the core difference between a critical deschooling and homeschooling:

> …this staunchly anti-authoritarian critique is where deschooling parts ways with the 'homeschooling' movement. Many homeschooling families reject the school system, yet maintain authoritarian family structures and in fact implement authoritarian pedagogical techniques with the home…the reactionary position may offer short term advantages, but in the long run it serves to strengthen our hierarchical society. (p. 84)

While I agree that many homeschooling families simply replicate the public schooling experience at home, including the authoritarian nature of compulsory schools, I read the word homeschooling less politically than the Lyn-Pilusos, and more as a helpful umbrella term that can be very useful to categorize the hundreds of different teaching or learning approaches that families use after the act of deschooling their children into a school at home. Dwyer & Peters (2019) define homeschooling with a more pragmatic lens as simply a substitute for public schooling writing:

> We use the term [homeschooling] to refer simply to parent-directed learning at home that substitutes, partially or completely, for attendance at regular school. This would encompass situations in which children learn at home by working their way through a packaged curriculum, so long as parents are overseeing this process. (p. 3)

I will use the term homeschooling as an umbrella term that encompasses all types of schooling done at home. I will use the term deschooling as both a verb to describe the act of leaving school and a noun as the time period in which a family adjusts to learning outside of compulsory public schools. I believe in and try to follow the Lyn-Pilusos' definition of a critical, social-justice oriented deschooling experience, however I call this unschooling, rather than deschooling.

The term unschooling was coined in the mid-1970s by fifth-grade teacher turned educational scholar John Holt, who purposefully used it in lieu of homeschooling to "avoid giving the impression that families were merely creating miniature schools in their homes" (Farenga, 1999, para. 26). Farenga (1999) concedes that Holt eventually gave up trying to distinguish between the two words and began using both in his writing because "homeschooling, for better or worse, was the term most people would use when discussing the idea that one can learn without going to school" (para. 26).

Though Holt popularized the terms unschooling and homeschooling, families have been teaching children at home for essentially humankind's entire existence, and in the United States homeschooling began long before it had a name (Dwyer & Peters, 2019).

I use all three words. I use deschooling to note the act of and time period of leaving school, homeschooling as an umbrella term for most education outside of public/private schools, and unschooling as the specific Illich-inspired, critical approach to learning at home that my family attempts to employ.

Process or Substance

One of Illich's (1971) issues with public education was the same issue he saw in society overall, that most people, and in particular the poor, had been sold on the idea that process equals substance, whether speaking of learning, health, or security. Illich (1996) posits an illogical logic he disagreed with — that the "more treatment there is, the better are the results" (1996, p. 23). Thus, requiring more education or teaching people more would directly result in more learning. So, if students were required to attend day school, preschool, kindergarten, elementary, middle, and high schools, and college, and work-related continuing education/training, plus an array lifelong learning classes, plus offered free classes in retirement, then we should have a utopian society of well-educated citizens because we've applied the maximum schooling treatments possible. Though the previous sentence perhaps describes our society's educational milieu today, I do not believe many would agree that we are anywhere close to a society chockfull of well-educated citizens. Illich explained the blurred logic writing:

> The pupil is thereby 'schooled' to confuse teaching with learning, grade advancement with education, a diploma with competence, and fluency with the ability to say something new. His imagination is 'schooled' to accept service in the place of value. Medical treatment is mistaken for health care, social work for the improvement of community life, police protection for safety, military poise for national security, the rat race for productive work. (p. 24)

It seems clear that today that as a society we still struggle to tell the difference in process and substance. Our health care systems are funded by the number of treatments prescribed and patients seen, not on the actual health and well-being of the person. Our

safety in schools, public spaces, churches, and our own homes seem more threatened than ever by mass shootings or other gun violence, despite police armed like armies and seemingly much of the citizenry also so armed. And our national security seems less secure despite a national military budget that eclipses the total spending of most countries in the world, much less our own domestic spending. Not to mention the fact no one has yet won the rat race. We seem to work longer hours, build more walls, stockpile more guns, pop more pills, build more hospital beds, build more prison cells, build more bombs, build more fighter planes and drones, add more cameras to our homes and towns and streets, and we go to school at night and on weekends to add more diplomas to our wall, so we can work more to pay for it all, we apply more and more treatment, add more and more to the process, yet the substance stays the same or worsens because as Illich writes we confuse substance with process. Thusly we also confuse process with substance, so in working more we are not richer, but poorer because time is the real substance we should treasure. And so it is with school, we leave those we love at home so that we can go off to spend our day at school to read, write, regurgitate, graduate, and repeat Ad infinitum, and if we ever come to the end of that schooling, we might ask if the years we traded left us with anything we couldn't have learned on our own by simply living our lives doing what we love with the people around us? I believe Illich would say no. I agree.

Commodification of Education

Hern (1996) observed that the debate and interest in Illich's writings after the publication of *Deschooling Society*, centered on public schooling and the idea of creating

a society free from compulsory schools. Routray (2012) also notes that much of Illich's writing "is often interpreted as a call to shut down schools" (p. 86). However, Illich some 25 years after publishing *Deschooling Society* wrote a forward and essay in Hern's 1996 book *Deschooling Our Lives* challenging the debate to extend beyond deschooling education (shutting down compulsory schools) to deschooling all of society. His critique was not just of schools, but a criticism of all the institutions of modern society from schools to healthcare to transportation (Zaldívar, 2011; Routray 2012). His challenge of the modern state's institutions from schools to hospitals to high speed trains was focused on his idea that these systems focused on their own benefit, replication, and survival, above, instead of, and at the cost of the benefit, welfare and survival of human beings, and indeed, the planet (Illich, 1996; Routray, 2012). Illich postulated that true freedom meant rejecting the commodification of services such as education, healthcare, policing, and public transportation that made these resources scarce. He suggested citizens could provide these services better in their own communities using their own freewill, judgement, and local resources, so that the institutions served the people not the other way around. One of my favorite examples used by Illich (1971) is how play or sport, in particular in schools, and I would add in post-secondary institutions, have become commodified spectacles of distraction that serve only to self-replicate and grow by schooling students, alumni, and community members into learning or confusing the process of cheering on the team as some substantive achievement, when in reality the only achievement is duping the schooled person into trading money, time, and effort in service of growing the industrial-sports complex. Illich wrote:

> (Games) which the schools use to raise income and prestige and in which they have made a substantial capital investment. As the athletes themselves are well aware, these enterprises, which take the form of warlike tournaments, have undermined the playfulness of sports and are used to reinforce the competitive nature of schools. (p. 81)

Illich wrote this in 1971, long before today's super commodification of sport on high school and college campuses in particular with million dollar stadiums, million dollar TV contracts, and corporate sponsored shoes, uniforms, and bowl games that have seemingly schooled society into viewing the primary purposes of post-secondary education to be the process of loyally buying and wearing school paraphernalia, both while a student and in perpetuity after graduation as alumni, in service of the promulgation of winning. Meanwhile, my own university library cut its collection budget by $1 million (Carol Grotnes Belk Library & Information Commons, n.d.), while the football team just got a new $45 million end zone facility (AppState Athletics, 2018). Appalachian State University seems to confuse process with substance, an example of Illich's self-serving, self-replicating institution that does not work to benefit the individual, society, or the planet.

Would Appalachian State benefit from a remaking of its society from a growing 1-A football powerhouse reifying sport above academics into a non-sport school focused on North Carolina's motto *to be rather than to seem*? I think so. Let's not seem like an institution committed to learning, let's be one. Let's deschool Appalachian State football saving the bodies of student-athletes who are now forced to trade the wear and tear of limb and concussive impacts on their brains for a shot at a *free* diploma, saving the

wasteful, unhealthy concessions that poison the health of fans and pollute the planet with leftover paper and plastic, and saving the financial investment that could be better spent on books, lowering tuition, or researching the important issues of our time.

I use this example to illustrate Illich's theory of how easily we as a society are schooled into supporting institutional endeavors that snowball into self-replicating wastes of resources, when instead we could be playing football with each other in our backyards or on the campus quads for free, and perhaps with more joy and playfulness. This is in essence the same argument Illich makes for deschooling — that we don't need to spend more and more tax payer money to create an ever-growing public school machine that becomes not only a waste of resources, but detrimental to those stuck inside it, when instead we could learn for free, and perhaps with more joy and playfulness, just by simply living and letting learning take place naturally with each other as we live.

While Illich's arguments are about society at large, I will focus from here forward on schools in particular. Illich advocated the remaking our educational system into a non-mandatory, personally funded, decentralized, and local endeavor. Homeschooling fits the bill for Illich's deschooling definition. It's not mandatory beyond minimal state reporting requirements. It has to be personally funded because no state monies are allocated for it, though the rise of crowdfunding for homeschools raises the specter of an alternate path of public funding though still not mandatory. Homeschooling is decentralized to the extent each family makes it so. And it's about as local as one can get since it typically happens at home, though the growth of online learning might be considered a path taking homeschooling toward more centralization, less localization, and perhaps more

commodification. As the Lyn-Pilusos noted (2008), certainly there are homeschools that do not fit Illich's concept of deschooling and simply seek to replicate the compulsory public schooling experience at home. These homeschools may be highly regulated, run on strict schedules, have rooms dedicated to teaching with chalkboards, desks, and worksheets, and an authoritarian teacher applying the process of learning. These do not fit Illich's theory of deschooling. I will instead focus on one type of homeschooling experience called unschooling that does fit into Illich's ideas of deschooling. Deschooling becomes the act of decoupling from compulsory public schooling into homeschooling and unschooling becomes the type of homeschooling I will choose to explore.

The Deep Gap

While accounts of unschooling exist in the literature, they are not plentiful. Why? Rolstad & Kesson (2013) suggest a fear among unschooling families that leads them to remain secretive and thereby becoming difficult to find, much less study. The researchers write:

> While homeschooling is legal in all 50 U.S. states, and has been slowly gaining in social acceptability, homeschooling families are still sometimes faced with hostility, and tend not to volunteer information about their educational status or activities. This is even more true of unschooling families, whose activities least resemble school, and are therefore least likely to volunteer their children for scrutiny by potentially prejudiced or judgmental observers. Unschooling families learn to navigate through the cracks and around the edges of what is considered to constitute 'appropriate' child experiences. (2013, pp. 30-31)

I feel that fear. Looking back, I believe one reason my dissertation was in process so long stems from perhaps an unrealized fear of putting my unschooling story in public.

Irrational fears of the Department of Social Services knocking on your door threatening to take your children from you. Irrational fears of a Sheriff's deputy along with local school officials knocking on your door telling you the state is here to take your children to school. Or perhaps not irrational. This fear is amplified in families with children who experience disability, at least in North Carolina, because like many states North Carolina has a program in place called Child Find that seeks to locate and identify children with disabilities under the guise of *helping* them into compulsory public schooling early. Education scholars estimate less than half of children with disabilities are identified prior to entering public school and that through early identification schools can reduce the costs of special education long term (Weglarz-Ward, Atwell, Rudenauer, & Morris, 2019). I notice the emphasis on cost savings, not on helping the child. This is what is erased from the poster — that Child Find isn't about helping the children, it's about lowering the cost of *helping* the children.

I often see these posters around town at the Medicaid office and the library advertising the Child Find program and to me the words are chilling. The poster asks the public to help the local school system, the state Exceptional Children's Division, and State Department of Public Instruction to located and identify children birth through age 21 who they might "suspect to have intellectual, physical, or emotional disabilities" (Project Child Find — Exceptional Children, n.d.) and to me it reads like a *wanted* poster in a Wild West saloon, the only difference being there was no reward listed. Child Find is an insidious example of Illich's commodification of education and how education becomes a self-serving, self-replicating machine devoid of respect for a family's human

rights for self-determination and choice. Child Find asks citizens to act as spies of the state to seek out children who they might suspect of experiencing disability. The poster reads, "without your help, children with disabilities may not be found" (Project Child Find — Exceptional Children, n.d.). It's more than posters. School systems have committees challenged to seek out and find these missing children with disabilities, I guess in case the citizen spies in the Medicaid office and library don't do their jobs for the state well enough. My spouse in her capacity as a special education teacher served on one of our local school system's committees. She recounts sitting in a conference room as this committee covered spreadsheets of data about local students suspected of having disabilities and then she realized that her own son was on the list though not named. He was a number all alone in one column with a label at the top "Refused Part B Services." Refused my ass. As Heather Newman (2009) writes tongue-in-cheek in her essay in the book *My Baby Rides the Short Bus: The Unabashedly Human Experience of Raising Kids with Disabilities*: "They were the experts, not me. Besides, it looked good in the paperwork" (p. 81). This may have made the committee's paperwork look good that a family *refused*, the word refuse abdicating them of responsibility. No one else in the room realized this was Kenyon. He received special education funding through the Children's Developmental Services Agency shortly after birth through his age out at three, but we made a conscious choice not to transition to special education services in public schools in hopes of bettering our chances at being the first family in our public school to be included in the regular classroom. My spouse, Janet, said this was the first time she realized the importance of language in this matter because the school system

saw us as *refusing services*, so we needed to be found, evaluated, and served. However, we viewed this as *declining* services. We knew what was available, we were just choosing to deschool ourselves and Kenyon from the compulsory system of special education schooling.

Call me irrational, but posters chockfull of polished and pretty stock images of children with disabilities calling on my neighbors to turn our family into the system under the guise of helping us, when in fact it's to help perpetuate the system by saving it money, yeah I'll deschool from that please. And we did. So I feel like the unschooled subjects Rolstad & Kesson (2013) describe as reluctant to share their stories. But I am sharing ours in the end. Selfishly, this might be because by the time this research is public, both my children will be near graduation. Liam, our oldest son, graduates from our unschooling homeschool (only because the state requires us to do so) in May of 2020, while at the same time expects to graduate with an associate degree from community college all at age 17. Kenyon will graduate our unschooling homeschool when he turns 16 in the summer of 2020. Then we will file the official state paperwork to close our homeschool.

Though research studies of unschooling are few (Rolstad & Kesson, 2013), they do exist. Even fewer studies involving both unschooling and disability exist and most of those involve a focus on learning disabilities. Research studies involving both unschooling and developmental and/or intellectual disability seem nonexistent. A Google Scholar title search for unschooling produced 95 results. Adding the words disability or disabled or disabilities produce zero results.

Part of the reason few accounts of disability and unschooling exist may be the different view on disability many unschooling families take. In Liberto's (2016) autoethnography of unschooling in Australia, she writes, "my child's dyslexia…is only a disability if you go to school" (p. 6). McGrath (2010) writes "I don't believe in special needs" (p. 27). McGrath (2010) writes that most of the labels related to special education or special needs don't apply outside the context of public schools. In general, the books I surveyed about unschooling don't address any type of disability.

Waltz (2009) describes the state of popular literature on the subject of kids experiencing disabilities, echoing Illich's ideas about commodification:

> YOU, parents of people with disabilities, and people with disabilities themselves, are the real experts. Much of the self-help literature out there is rubbish churned out to make a buck, and some of it doubles the insult by being incredibly patronizing on top of it (p. 301).

Newman (2009) comes closest to writing about both unschooling and developmental/intellectual disability in her essay *Accidental Unschoolers* in the larger volume of writings by parents of children with disabilities *My Baby Rides the Short Bus: The Unabashedly Human Experience of Raising Kids with Disabilities*. The book is genuinely unabashed, as many parents of kids experiencing disability are, with its stories of love, hardships, and mostly criticisms of special education inside compulsory public schools. However, Newman's 2009 essay details not only her hardship with schools, but her deschooling process toward and finally into unschooling. She writes:

> Trying to find resources at bookstores or online about unschooling kids with developmental disabilities leaves a lot to be desired. What little I have found focuses on schedules, curriculum, or is heavily slanted towards information on autism and ADHD. We are willing and able to find our own way with our boys, but it would be nice to have some connections with people who understand what we are doing and are on a similar journey. (p. 85)

Newman's statement represents the deep gap my research hopes to begin to fill. To articulate at least one more story of a family unschooling a child with a developmental/intellectual disability, with a hopeful heart that more will follow.

Deschooling Sparks

Beyond theorizing a society without compulsory schools, laying the groundwork for scholars like John Holt to articulate the idea of homeschooling in the mid-1970s (Farenga, 1999), Illich's writings served as an "entry point into deschooling for many people" (Hern, 1999, p. 23). This is true for me as I read the book 45 years after it was written as a required reading for a graduate class. The volume, though a short and quick read consisting of seven essays and little over 100 pages, started a significant learning transformation in me and my family that eventually led us to create our own deschooling journey, which we have enacted as unschooling over the past nine years. I agree with Hern that Illich's writings may have done the same for many homeschooling families who found his books, but more likely it was later authors who amplified Illich's theories through writing more accessible and popular texts — authors such as John Holt and John Taylor Gatto, who collectively have sold millions of books on topics of homeschooling. In a 2013 survey of 232 families practicing unschooling a majority cited an author that

played a role in the family's decision to unschool with the most-named author (127 families) being Holt and second most (52 families) being Gatto (Gray & Riley, 2013).

For most homeschooling families there was an encounter that sparked the interest in deschooling. Coupled with a dissatisfaction with public schooling, the spark often led to wild fire search for information on how to deschool and how to start homeschooling. Most of those searches, whether online or on bookshelves, led to the works of Gatto or Holt. For me it was Illich's writings that led me to Gatto and Holt.

In homeschooling circles, some naively dismiss Holt because he never had children of his own (Farenga, 2018), but others hail Holt as the father of homeschooling (Martin, 2009) or even the grandfather of homeschooling (Hern, 1996). Holt was a longtime advocate for homeschooling and published the first homeschool/unschool magazine called *Growing without Schooling,* which was published continuously for 24 years, even after Holt's death. His books included *Instead of Education: Ways to Help People Do Things Better* (1976), in which Holt articulated the idea of homeschooling as an act of civil disobedience and introduced the idea of removing children from compulsory public schooling via legal or underground means.

Farenga (1999) wrote of Holt's appeal to homeschoolers, "While the education establishment barely recognized this particular book (*Instead of Education*) of Holt's, it struck a chord with some parents" (para. 12). Farenga explained this harmony Holt struck in the homeschooling community writing:

> Holt urged educators and parents to catch the spirit of unschooling, be inspired by the variety of approaches and methods homeschoolers show, and reconsider assumptions about schooling based on what ordinary parents, as well as some alternative schools, were doing with children. It is in this regard that Holt is so different from many education writers and school reformers. He never felt that only trained teachers should teach students. Holt never studied education in school, which he considered an advantage since his mind was thus not full of assumptions about what kids can and can't do. He was a practitioner who learned from what worked and what didn't, in his experience, and he felt very strongly that any concerned adult could do as well or better than he in this regard. (para. 12)

Holt's writings reinforced the belief that any family can deschool and homeschool their children giving confidence to families to exit compulsory schooling and create their own paths toward learning. Still, making the leap from a schooled life to a deschooled life involves answering a question every homeschool family has to face.

Who Can Teach?

Who can teach? It's a central question of schooling and a major theme of deschooling and homeschooling. To teach in most compulsory schools there is a long list of qualifications, however for 16 states, including North Carolina, all you need is a high school diploma or equivalent to homeschool. Regardless of state requirements, the question remains at the heart of the homeschooling movement. Who can teach? For Holt, the answer was anyone, except perhaps trained educators. Holt said being trained as an educator might hurt one's ability to homeschool:

> I wouldn't say that a person was disqualified from doing it (homeschooling) because they had training in education, but I would have to say that practically everything they taught you at that school of education is wrong. You have to unlearn it all. I never had any of that educational training…the children don't have to learn physics or math from you. There are plenty of people to learn from;

> there are plenty of books, there are plenty of extension courses…there are people who only have high schooling, or may not even have finished that, who are now teaching their children at home and doing a very good job of it. (Bumgarner, 1981, para. 10-11)

I teach college students and have for the past 20 years. My spouse taught in public school for 17 years and now also teaches college students. The fear of not knowing how or what to teach was not an obstacle to our family choosing to deschool. However, for many families I speak with who express interest in homeschooling, this is one of their biggest concerns (the other being financial). I think this why Holt's writings resonate with homeschoolers, because he was not a formally-trained educator, yet he wrote in a way that not only encouraged folks to deschool, but showed them pragmatic ways to do so, even if they've never considered themselves a teacher. Holt may have thought my family unsuited to teach because of our background in teaching. Farenga (1999) agreed with Holt's assessment of those claiming to be teachers, writing:

> Trained teachers are not trained in teaching, but in classroom management, i.e., in controlling, manipulating, measuring, and classifying large numbers of children. These may be useful skills for schools, or people working in schools. But they have nothing whatever to do with teaching -- helping others to learn things. (para.13)

Holt's work appeals to me and I think to others in homeschooling circles, because he was not dogmatic about the process of homeschooling from who should teach to how to where to when. Holt acknowledged the wide spectrum of practices that fall under the homeschooling umbrella and perhaps more importantly the wide range of reasons families might choose to deschool. The decision to leave compulsory public schooling is

typically very personal and it becomes almost impossible to find common themes that bind families that homeschool. Farenga (1999) said homeschooling "often led to strange bedfellows, or mixed allies" (para. 13). Holt's writing echoes that sentiment:

> Those who…want to take or keep their children out of schools, may have very different, in some cases opposed reasons for doing this. Some may feel that the schools spend too much time on what they call the basics; others that they don't spend enough. Some may feel that the schools teach a dog-eat-dog competitiveness; other that they teach a mealy-mouth Socialism. Some may feel that the schools teach too much religion; others that they don't teach enough, but teach instead a shallow atheistic humanism. (1999, as cited in Farenga, para. 13)

Families may have very different reasons to choosing to homeschool and the public has many, often polar, views of homeschooling as noted by Dwyer and Peters:

> Threat to democracy, or bulwark against tyranny? Enslavement of the mind, or last refuge of human independence? Stunting of children's social development, or more natural and nurturing site of cooperative interaction? Violation of children's rights, or recognitions of parental entitlement? Homeschooling—pervasive in colonial times, an anomaly a half century ago, today a national movement—now has this two-faced nature, one ugly and threatening as seen by critics, the other beautiful and wholesome in defenders' eyes. The reality is that today it is no one thing. (2019, p. 1)

Whatever one's view of homeschooling, it has a common history that starts with Illich's theorization of deschooling, which led Holt to theorize unschooling and foster homeschooling by writing and editing books and magazines that gave families pragmatic paths to enact their own homeschooling/unschooling journeys.

The Growth of Homeschooling

Holt died of cancer in 1985, so he didn't get to see the exponential growth in homeschooling that took place from 1980 to today (Cheng & Donnelly, 2019). He did predict a slow start to the movement. While I have reservations about Holt's problematic analogy to slaves, because no conditions inside compulsory school even come close to the horrors of slavery, I will include Holt's metaphor here to put forth the essence of what he proposed in his own words:

> …a new Underground Railroad to help children escape from schools. Some may say that such a railroad would be unfair, since only a few children could get on it. But most slaves could not escape from slavery, either, yet no one suggested or would suggest that because all the slaves could not be freed, none should be. Besides, we have to blaze a new trail if only so that others may follow. The Children's Underground Railroad, like all movements of social protest and change, must begin small; it will grow larger as more children ride it. (p. 218)

Holt's predictions to some extent have come true as more and more families choose homeschooling and at a faster and faster rate. Cheng and Donnelly (2019) point to the 1980s as the start of rapid growth in homeschooling (p. 259) with the National Center for Education Statistics (NCES, 2019) in the U.S. Department of Education measuring the number of homeschooled children by 1999 at 900,000 students or 2 percent of the United States K-12 population. Since 1999, the number of homeschooled students has nearly doubled to 1.7 million students, according to the latest numbers gathered by the NCES in 2016 and released in 2019. The NCES report breaks down the percentage growth of homeschoolers from 1999-2016 by elementary grades 5-12 growing 79%, middle school grades 6-8 growing by 114%, and high school grades 9-12 growing 124%.

Still homeschooling makes up only three percent of the 47 million students in the United States. As a comparison, public and charter school enrollment combined only grew 1.4 percent over the same time period. Cheng and Donnelly describe the growth in homeschooling at the turn of the century as "a burgeoning movement" (p. 259), adding that almost 20 years later homeschooling is now a "growing global phenomenon."

The growth nationally is at least mirrored, if not amplified in North Carolina, a state listed as a moderate state in regards to homeschooling law, by the pro-homeschooling Home School Legal Defense Association (HSLDA), which not only ranks states by the ease of homeschooling law, but provides pro bono legal defense to preserve the "constitutional right of parents and others legally responsible for their children to direct their education" (2019). I have always regarded North Carolina as an easy and safe place to homeschool, mostly because of the simple and straightforward requirements: send a simple notice to the state to open a home school, check a box on a form to operate as either a religious or non-religious homeschool, keep a copy of immunization and attendance records at hand, take one standardized test per year (you don't even have to send in the results or even open them, you just have to take it and keep the results on file), and finally let the state know when you close the school. That's it! I would mention North Carolina does require a high school diploma or the equivalent in order to homeschool, which does prevent some families from legally homeschooling.

I disagree that North Carolina should be ranked moderate by the HSLDA. Dwyer and Peters (2019) concur writing, "in most states, permissive homeschool laws enable these [homeschooling] parents to do this with impunity, because the laws require no real

oversight of homeschools; indeed, many do not even require parents to notify school officials of an intent to homeschool" (p. 1).

However, in defense of the HSLDA rankings, 11 other states have no requirement to homeschool, 16 states only require parents to notify the state of opening a homeschool, and like North Carolina, 16 other states have moderate requirement that involve test scores or some annual progress reporting. That leaves six states the HSLDA ranks as high regulation meaning additional requirements above notification, annual testing, and progress reports, to curriculum approval, teachers' qualification, and home visits. The thought of home visits and curriculum approval really makes me thankful to live in North Carolina where I find homeschooling requirements set forth by state law and the North Carolina Division of Non-Public Education (NCDNPE) easy to meet.

North Carolina homeschooling has grown from the first reporting period on file in 1985 from 809 students statewide to 27,978 students in 1999 and increasing 400% over the last 20 years to 142,037 homeschooled students in 2019 (NC Division of Non-Public Education, 2019). In my home county of Watauga, if you put all the homeschooled students into one school, it would be the second largest school in the county with 735 students in 2016, that's compared to the largest school in the county with 877 students. Homeschool students represent 14% of the 5,228 students in Watauga County. Though Watauga County Schools have not released numbers since 2016, Watauga's homeschool numbers grew in 2019 to 824 students, according to the NCDNPE.

I certainly feel the growth anecdotally through my own experiences having watched students at my sons' public school disappear as they moved through pre-K to

third grade. I would ask my oldest son, "I haven't heard anything about Jill or John lately?" He would often reply, "oh, they are homeschooled now." This continued until we exited public schools half way through the third grade for our own journey.

The Problem with Education

Illich's bold stance on removing compulsory schooling from society was revolutionary to me and I'm glad I read it first, before his later works some 25 years after the original was published, where Illich revised and softened his ideas on removing compulsory schooling from society (Illich, 1996). He wrote:

> Now I realize that I was largely barking up the wrong tree...I grew more and more dissatisfied with the text, which, by the way, did not argue for the elimination of schools...the book advocates for the disestablishment of schools, in the sense in which the Church has been disestablished in the United States. By disestablishment, I meant, first, not paying public monies and second, not granting any special social privileges to either church- or school-goers. (pp. vii-viii)

Illich (1999) goes on to clarify what he called his mistake -- that the justification for deschooling or dismantling of schools was to *improve* education. He feared the resulting vacuum from eliminating schools would result in the rise of a fanatical need for education that would remake "the world into a universal classroom, a global schoolhouse" and create a world where "this talk of lifelong learning and learning needs has thoroughly polluted society, and not just schools, with the stench of education " (p. vii). He argues that the mistake was a focus on process, rather than orientation writing that he shouldn't have been trying to improve education by deschooling the process, but instead questioning the aim, questioning the very need for education in the first place. In

his later writings, Illich reorients his focus on the problem of education as a commodity, as a scarce resource one needs to consume or get from professionals who are in the business of selling it. The issue of scarcity applied not just to education in compulsory schooling, but even when deschooling, homeschooling, or unschooling. Illich (1996) explains:

> I had questioned schooling as a desirable means, but I had not questioned education as a desirable end. I still accepted that, fundamentally, educational needs of some kind were an historical given of human nature. I no longer accept this today...if the means for learning (in general) are abundant, rather than scarce, then education never arises--one does not need to make special arrangements for learning. (p. ix)

Illich asks us to consider the historical circumstances that allowed *the idea of educational needs* to arise. One writer advocating deschooling, John Taylor Gatto, details that history in his books *Weapons of Mass Instruction* and *Dumbing Us Down*. Gatto's writings are not often quoted by educational scholars, but by the dozens upon dozens of what I will reluctantly refer to as vanity books. The advent of print-on-demand technology has given rise to a burgeoning field of new authors who don't need a printing press or publishing company, but only a Word document and an internet connection. Because of the need for at least one parent to quit traditional paid work in order to make most homeschooling arrangements work, these families often seek creative means and multiple income sources to pay the bills of everyday life. Writing, uploading, and your own homeschooling experiences is a natural fit for many of these families who enjoy *mailbox money* checks for sales without any further work beyond the initial writing and

upload. There is even a book *Crowdfunding Your Homeschooling Expenses* (2015) by the pen named author Charity Grant. More than 1,6000 homeschool crowdfunding campaigns are listed on one of the largest platforms GoFundMe.com (2019).

A simple keyword search of books on Amazon.com (2019) shows more than 50,000 books, many of which are vanity books written by homeschooled families. This show the variance of homeschooled lives in America today. The same keyword search for unschooling produces more than 800 books. For both of these search results I've found it impossible to get an accurate count through filtering because some of the results are not books, but products tagged as books by product producers (journals, cards, games, paper, notebooks, planners, etc.) reinforcing Illich's (1996) idea of education as a commodity and providing an example of his *mistake* in *Deschooling Society*, that deschooling is just another process subject to commodification (p. ix). Regardless of the actual number of titles, the choices for books about homeschooling and unschooling are wide and variant. The titles often use a variation of the word homeschooling or unschooling by placing another word in the place of home or un, however I believe most of these approaches would fall under the umbrella of deschooling: unschooling, radical unschooling, unhurried homeschooling, sage homeschooling, wild schooling, Christian unschooling, fun schooling, joyful unschooling, road schooling, God schooling, vagabonding, free schooling, relaxed homeschooling, project-based homeschooling, homeschooling with pets, unschooling dads, do-it-yourself unschooling, world schooling, slow homeschooling, mindful homeschooling, courageous homeschooling, self-directed schooling, unschooling in Portland, adventure unschooling, uncurriculum, willed

curriculum, free educating, intuitive unschooling, extraschoolers, Catholic relaxed unschooling, Zen schooling, unplanned homeschooling, no sweat homeschooling, reskilling unschooling, flexi-schooling, and learner managed learning.

I believe Gatto's writings are more cited in these books not only because of his frequent lecture gigs, especially for homeschooling organizations, that put him in front of homeschooling families, but also because Gatto writes with a literary authority that uses vivid storytelling and metaphors that make his ideas more accessible to homeschooling parents who are mostly not academics.

While other scholars such as James Fraser and his book *The School in the United States* and Joel Spring and his *The American School* offer more complete and comprehensive histories and in Spring's case a critique of schooling, Gatto translates that information into terms relatable to the experiences of homeschooling families. Gatto (2010) taught in public schools for 30 years before resigning during the year he was named New York state's teacher-of-the-year (p. 215). He cites Holt as a primary influence on his thinking. Gatto characterizes the history of public schooling as a weapon:

> Most historical accounts of schooling are so negative you have to wonder how this exercise of pedagogy ever passed the test of time with its original parts nearly unchanged. It must yield some benefits, but what those are and for whom isn't so clear…I feel compelled to plant this flag firmly while I have time left — school is not a good place for your kids. If they are swarmed by friends and win every award the place can offer it changes nothing. From the first month of my teaching career of 30 years, I realized that intellectual power, creative insights, and good character were being diminished in my classroom and that indeed I had been hired for precisely that purpose. I was a clerk in a vast penitentiary; the rules and procedures were the guards. (pp. 100-101)

I believe Gatto is popular with homeschooling families (Gray & Riley, 2013), and in particular those who write up their stories for publication, because he reinforces what many homeschooling authors and readers want to hear — school is bad, and you need to take your kids out. Gatto famously labeled public schools *psychopathic* in his New York City Teacher of the Year acceptance speech in 1990, saying:

> Although teachers do care and do work very, very hard, the institution is psychopathic — it has no conscience. It rings a bell and the young man in the middle of writing a poem must close his notebook and move to a different cell…. (p. 22)

In his book *Dumbing us Down*, Gatto (2005) emphasizes what many deschooling families seek as an alternative — interest-based learning that focus on a learner's strengths rather than identifying and focusing on the learner's weaknesses. On the occasion of Gatto's death in 2018, Farenga (2018), described the deschooling advocate in a piece written for a blog on John Holt's *Growing without Schools* web site:

> My favorite writings by Gatto are the ones about how, as a teacher, he helped individual students learn and grow by working with their interests and strengths. They are powerful to read and continue to influence many people, young and old, to try alternatives such as homeschooling, unschooling, and alternative schools. (para. 26)

Farenga (2018) said Gatto incorrectly predicted the collapse of public schooling under its own weight at the turn of the last century, but after Gatto experienced a stroke

Farenga said Gatto shifted his position to a new stance that appears to be the tact deschooling is taking today. Farenga relates what Gatto told him while in the hospital bed:

> He told me that alternative schoolers were better off building a new system of education that would appeal to more and more people, causing the public to eventually leave the conventional system. 'We have to beat them at their own game,' is how he summed it up to me. (para. 25)

I believe Gatto's shift reflects my own thoughts on education and mirrors the thoughts of many others who choose to deschool. In my family's case, we spent nearly four years trying to change the public school system from within and found ourselves with a choice between sacrificing the health and well-being of our children and ourselves as parents too, to borrow a phrase from Gatto, the psychopathic school system, which had proved itself to us as just that, or use the privilege our lives afforded us to to deschool our lives. We did the later and it has made all the difference.

The First Unschool

Illich's later writings in the 1990s capture the nature of deschooling better than his 1971 book *Deschooling Society*. However, he admits the book "helped some people reflect on the unwanted social side effects" (p. vii) of the institution of education. Certainly, that is true of me because I discovered *Deschooling Society* first.

Illich's writing sparked my own reflection on the effects of public compulsory schooling on our family and also increased my interest in learning more about deschooling. This spark was fueled by Illich's writings and the flame lighted the way to

my family's decision to deschool/unschool our children. Without reading his initial and bold stance on deschooling, perhaps my journey would have taken longer or never launched at all.

I feverishly highlighted and wrote in the margins of my copy as I read Illich's ideas that troubled me to the core by shattering my notions of self as a teacher and perhaps as parent, too. His ideas compelled me to reflect on my life on the production side of education, but on the consumption side having spent nearly 30 years of my life as a student. I wrote in anger and joy as his writing jolted me from many assumptions I'd been schooled to accept as truth all my life. Illich (1970) writes:

> We are all involved in schooling, from both the side of production and that of consumption. We are superstitiously convinced that good learning can and should be produced in us -- and that we can produce it in others. Our attempt to withdraw from the concept of school will reveal the resistance we find in ourselves when we try to renounce...the pervasive presumption that others can be manipulated for their own good. No one is fully exempt from the exploitation of others in the schooling process. (p. 48)

I bristled at the thought of my efforts as an educator as exploitation but reveled in his accurate predictions of schooling's negative impact on my own children, even if I was complicit in that exploitation. I experienced the resistance he described as I began to consider deschooling my life. Reconciling the difference in being a producer of education and simultaneously a consumer of education is something I'm still attempting to grip today as an educator in his 20th year of teaching. However, I have Illich (1971) and his *mistake* to thank for sending me down a path where I can consider the troubling possibility he penned that remains at the heart of deschooling and in particular

unschooling, that "most learning requires no teaching" (p. 47). At the time Illich wrote these words, he also had created a deschooled university frequented by many of the scholars who went on to write the transformative texts that shaped my and my family's unschooled lives decades later.

For 10 years Illich co-directed the Center for Intercultural Documentation (CIDOC), which had by the time he was writing *Deschooling Society* in the late 1960s had become a destination for avant-garde intellectuals, radical thinkers, and counterculture leaders from around the world (Bruno-Jofré & Zaldívar, 2012). Illich (1996) writes about the educational scholars gathered at the CIDOC to "address the futility of schooling" (p. vii) most of whom form a who's who of scholars that I was first introduced to during my coursework in my educational leadership and cultural studies graduate program: Paulo Freire, Paul Goodman, Jonathan Kozol, Joel Spring, George Dennison, and John Holt. Illich described the CIDOC as "a free university, hosting seminars which attracted reform-minded thinkers from around the world" (Illich & Cayley, 2005, p. 10). Inman (1999) describes the CIDOC as a non-structured antischool and a "living model of Illich's though on learning" (p. xi). Inman continues:

> Illich's CIDOC—part language school, part conference center, part free university, part publishing house—was designed not so much to train missionaries as to keep all but the most progressive of them away…CIDOC became Illich's anti-school, existing as a source of criticism for all secular orthodoxies of development. (pp. 11-12)

At its height and end 10 years after it began, the CIDOC had more than 60 employees, a library of 15,000 books, and a large complex of rooms for living and learning (Inman, 1999).

The CIDOC is important because of its role as a crucible for educational thinkers of the time who shaped Illich's ideas on deschooling. Freire was there and on the cusp of publishing *Pedagogy of the Oppressed* (1970). Freire joined the other educational scholars in reviewing, critiquing, and debating Illich's writings presented as essays to the group before Illich revised and published them as *Deschooling Society* in 1971 (Illich, 1996). In addition to hosting, housing, and holding these thinkers together in debate of the issues of the time, the CIDOC served as a model for Illich's concept of deschooling.

Though not associated with the CIDOC, Frankfurt School scholar Erich Fromm also resided in the same resort town of Cuernavaca, Mexico and not only became Illich's neighbor, but his friend who critiqued Illich's work and wrote introductions for his publications (Bruno-Jofré & Zaldívar, 2016). The CIDOC is important as an extension of the work of The Frankfurt School. I would draw a connection backward in time to The Frankfurt School and forward to today's educational milieu.

The parallels between The Frankfurt School and the CIDOC extend beyond the presence of Fromm. Both The Frankfurt School and the CIDOC were collectives of intellectuals living and learning together in a turbulent post-war time where authoritarian regimes were rising. The Frankfurt School scholars worked in the shadow of the first World War and the turbulent age between then and the second World War that saw the rise of fascism. The CIDOC scholars worked in Mexico during a time that saw

authoritarian regimes rise and take power across Central and South America. In addition to a connection from the CIDOC backward in time to The Frankfurt School, I would connect a thread to today's world where we see populism, neoliberalism, and authoritarian leaders rising.

The scholars of the Frankfurt School articulated critical theory, while scholars at the CIDOC focused on Freire's (2000) notion of praxis — combining theory and practice in a way that is transformative. I would move now to explore critical theory as a connector between these educational moments of the Frankfurt School's founding 100 years ago, 50 years ago the work of scholars at the CIDOC, and today.

Critical Theory

The themes of Illich's works have roots in critical theory. Illich's utopian vision of a deschooled society and the world's ability to achieve such a vision echoes critical theory described by Bronner (2011):

> Critical theory always had an anticipatory character. Its advocates projected the transformation of everyday life and individual experience…[The Frankfurt School] sought to bring about a new utopian sensibility devoid of cruelty and competition. (pp. 6-7)

No matter where one argues the roots of critical theory began, one group of scholars named critical theory and ushered it into an academic consciousness — The Frankfurt School. Now 100 years after the founding of the Institute for Social Research or the Frankfurt School, I ask not where are we, but are we back where we began? Have we come full circle? The beginning of the 20th Century gave Western society a

tremendous burst of change as the last vestiges of the agrarian age gave way to the industrial age and ushered in modernism. According to Bronner (2011), it was in this crucible a group of German-Jewish scholars that came to be known collectively as the Frankfurt School came together in hopes of solving society's ills that arose during this time of tumult. Perhaps the most important achievement of this think tank was the articulation of a critical theory of society. Is the time period that gave rise to the Frankfurt School so different from today? At the beginning of the 21st Century the world is experiencing a tremendous burst of change as the last vestiges of the modern industrial age give way to postmodernism and an unnamed age we keep trying to nail down with *Information Age* or *Digital Age* or *Global Age*. The Frankfurt School evolved between two world wars. Today, though not labeled *world war*, we are experiencing nearly two decades of multi-nation wars. In the survival of capitalism over the failure of Marxist predictions of its fall in the face of socialism, the Frankfurt School witnessed the rise of fascism and communism in response to capitalism (Bronner, 2011). Today, after the fall of communism two decades ago, the rise of hyper-capitalism leaves questions of what will rise politically to respond to it? A return to fascism? Are we seeing this in the era of Trump? Something new? In America, the excesses and stratification of wealth in the Roaring Twenties ended with the crash of 1929 and resulting Great Depression. Today, the excesses and stratification of wealth in the first two decades of the new millennium may or may not have culminated in the crash of 2008 and ensuing Great Recession. The Frankfurt School arose in the midst of a technology revolution from electricity to lights to recording to radio to telephone to movies to cars to planes to the atomic bomb, all of

which fundamentally changed how people lived and how they understood society and the world. The explosion of technological innovation created a palpable tension as most people moved into industrial living from the agrarian life that had been basically unchanged for the centuries since the transition away from a hunter/gatherer society. Today our technological revolution includes: Internet-based technologies such as social media, search engines, and wikis; genetic engineering from the human-genome project to genetically modified foods to cloning; surveillance technologies from global positioning to data-mining to electronic monitoring to biometrics; and computer technology that continues to become faster, smaller, and part of, or extensions of, our bodies such as smartphones. Like the technology-induced tension in society that gave rise to the ills the Frankfurt School sought to solve, today our technology marks society's move from the modern industrial age that has remained basically unchanged for nearly 100 years centering on capitalistic production, toward an undefined age that will be markedly different than the age that preceded it. The remarkable parallels between today and the time period that gave birth to the Frankfurt School, which gave birth to critical theory, give rise to a reconsideration of critical theory. Bronner (2011) echoes this call, "critical theorists today must look backward in order to move forward" (p. 8). If the Titanic, Hitler, Auschwitz, Hiroshima, and Nagasaki were the Frankfurt School's ills, what are our ills today? What represents our future suffering in its many possible forms: the collapse of capitalism, pandemic disease, alien invasion, or global climate disaster? The nearly 100 years since the inception of the Frankfurt School has had significant moments of social justice change. Society witnessed the rise (though still a long way to go) of

women's, civil, sexual, gay, and disability rights. Will these rights be fully realized in the next 100 years? Will we add animal, planetary, or even universal rights? Or perhaps the barbarians are already at the gates ready to invade Rome?

If our time reflects the time that gave birth to the Frankfurt School, is there an equivalent think tank today? I answer *yes*. I see the work of qualitative scholars, especially those engaged in critical pedagogy, as the current equivalents of the Frankfurt School. An emerging field of scholars breaking free of the bonds of formalism into new spaces of inquiry in hopes of surviving the unknown calamities ahead will usher in a new century that fulfills the social justice promise not in an information age or digital age or global age, but in what I would call an organic age of connection. This new organic age values connection and chaos and complexity. This new age does not seek a universal theory that becomes the next status quo, but instead seeks to play its part in the evolving nature of the creation of a socially just world. Could we build a democracy in which justice prevails? Can we imagine a world where power is distributed equally? Can we create a society where all people have access to basic goods? Is it possible to live without fear? It becomes difficult to imagine a new way of being while living in our current age of authoritarianism where a toothless citizenry accepts free market fundamentalism as a template for living and profit as a purpose in life. In a video interview with the BBC's Bryan Magee (1978), Frankfurt School member Herbert Marcuse downplayed the ability of critical theory to address the world's problems, saying he anticipates the destruction of society, "as society progresses, more is repressed, aggression rises, and destruction happens." I do not agree with Marcuse. I'm hopeful we can turn the tide.

CHAPTER III

METHODOLOGY

Autoethnography can be like creating a quilt-like academic product in words (Dean, 2018; Rubinstein-Avila & Maranzana, 2015) and though many ways of creating autoethnography exist (Ricci, 2003) the end result is typically text in print. Writing and rewriting becomes a method of inquiry. Autoethnographic research is a process of many tools including, but not limited to observing, listening, gathering artifacts, journaling, reflecting, sketching, remembering, creating, interviewing, reading, writing, and revising, and returning through the process again, again, and again. A final product emerges from the effort. The research writer is, as Steinberg (2011) describes, both inserted and intertwined in the work. In this research, I used a method of autoethnography to create a patchwork, quilt-like story of stories that narrates my family's deschooling/homeschooling/unschooling journey over the past 13 years. The research process included visiting and revisiting the sites of inquiry, the writing of reflections, memories and remembrance, journaling, composing poetry, gathering of artifacts such as school worksheets, papers, and report cards, as well as photographs and videos, reading, surveying social media posts, more writing, and circling through the data over and over creating narratives along the way, and finally weaving them into an autoethnographic story.

My methodology imagines new ways of constructing knowledge work in the academy, including how to represent and communicate research, especially interpretive work like autoethnography. My own knowledge work, informed by critical theory, is created in a circular process of researching, writing, and returning, that has forced me to not etch my research aims in stone, but to articulate an always fluid, always shifting, always contested, always open list of research possibilities to explore as the research unfolds. For example, when I began my research, I thought my research would be only about deschooling and my family's exit from compulsory public schools and that I would use a research method of bricolage (Kincheloe, 2001, 2005, 2008; Denzin & Lincoln, 2000, 2005, 2011; Lévi-Strauss, 1968). As the research unfolded, it became clear that deschooling was merely an entry point into a larger story that included homeschooling and an even larger story of unschooling, and that bricolage was not the best method to use to answer my research question. In my search for the appropriate method to relate these stories, I found autoethnography, or perhaps found it again, because in truth, as Ellis writes of a similar epiphany in her journey as a researcher (2013), I discovered that I have been an autoethnographer all my life.

As a researcher, I sought to enact what Denzin (2000) describes as a critical, literary, interpretive, and performative autoethnography (p. 403). Denzin describes this type of research and resulting academic product:

> It is a way of being in the world that avoids jargon and huge chunks of data. It celebrates the local, the sacred, the act of constructing meaning. Viewing culture as a complex process of improvisation, it seeks to understand how people enact and construct meaning in their daily lives…The play of power in daily life is best

> revealed in performance texts, in narrative accounts which tell stories about how humans experience moral community. (p. 401)

My autoethnographic method is the creation of a series of narrative accounts in the vein described by Dezin above, woven into a text in a literary fashion that serves to focus attention on issues around social justice in hopes of moving readers to action. In short, as a researcher I see my work as an act of explaining relations, much like Kincheloe (2004) explains theory, "[it] is not an explanation of the world — it is more an explanation of our relation to the world" (p. 2). So too, must my research seek to communicate relations over universal explanation. I do that through storying my life, and in particular, my life deschooling my children, including a child who experiences disability, as a life focused on unschooling.

Autoethnography

Goodall (2000) wrote *Writing the New Ethnography* detailing the task of an ethnographer to learn fieldwork, learn to write, learn who you are, and learn to meaningfully connect the three (p. 7). Nearly 20 years ago now, what Goodall called *the new ethnography*, was autoethnography (Ricci, 2003). No matter which wording you choose, Goodall's words describe my research approach, though I would add in a qualification that the process of learning fieldwork, learning to write, and learning who you are, is never static or complete and is an ongoing endeavor that continues through each new research project. In articulating a new ethnography or autoethnography, Goodall describes many of the tensions between so-called *traditional* research and the

new ways of doing research in the 21st century. I certainly, as an autoethnographer today, feel the same tensions Goodall (2000) described at the turn of the century:

> The major problems or challenges facing writers of new ethnographies are those derived from a deep, disciplinary misunderstanding of purpose. I think this misunderstanding is made worse by trying to associate the evaluative and ethical standards for traditional scholarly work with what is clearly an interpretive genre that does not share the narrative goals or argumentative values of traditional scholarship…what I hope we are doing…is evolving to a *higher state of scholarly consciousness*. The measure of our human worth will be in the quality, and the difficulty, of writing through the questions we ask, as well as the ways in which our stories speak to the communicative needs — the souls and hearts and minds — of other human beings. (pp. 197-198)

Autoethnography is about both about writing to answer questions and speaking to hearts and minds in the process. The end goal can be easier to understand than the process. Goodall (2000) describes the new ethnography as a task of fieldwork, drafting, returning, writing, revising, returning, re-writing, cutting, adding, returning, reading, revising, and choosing a place to stop. Some might say autoethnography doesn't have fieldwork, but I believe it can. Fieldwork in autoethnography might involve some of the typical work of an ethnographer. Chiseri-Strater and Sunstein (2012) describe the ethnographer's task as "talking, listening, recording, observing, participating, and sometimes even living in a particular place" (p. 1). The same is true for the autoethnographer, who is often living the life the researcher is writing about. Even if writing past events the autoethnographer can return to the field of the research, even years later, to observe, reflect, and record. The autoethnographer can gather artifacts, like a typical ethnographer, from journal entries to photographs to video to blog posts to

emails to any number of objects that might help in the task at hand. This task, as described by Chiseri-Strater and Sunstein (2012), mirrors Illich's (1971) description of a deschooled life as simply living. They write, "ordinary living involves all the skills of fieldworking — looking, listening, collecting, questioning, and interpreting," (p. 1). This thread of ordinary living runs through not only deschooling/homeschooling/unschooling, but ethnography, autoethnography, and fieldwork. The difference is the researcher is conscious of the effort and tools and writes about that process, so the researcher is doing more than simply living, but reflecting on that living in some systematic way (Chiseri-Strater and Sunstein (2012).

I believe critics of autoethnography, don't see the connections between it and Goodall's new ethnography. Autoethnography is not fiction. Critics might see a researcher sitting in a room writing remembrances and yes, that is how some autoethnographers write research and I don't want to reify one method as the right way to research. Instead, as (McDonnell, 2017) implies, there is no one correct way to do autoethnography:

> Perhaps one of the biggest hurdles in engaging in autoethnography is that this one term, like other research methods, actually encompasses a wide range of approaches, and, it must be said, it is not instantly clear what an autoethnographic study looks like…the "doing" of autoethnography is not necessarily immediately evident; however, this complexity and variety means that I can find my own space, define my own position, and shape my own methods. (p. 65)

I too, must *find my own space, define my own position, and shape my own method*. For me, that starts with the end purpose of the research. Goodall (2000) writes of

a *higher scholarly purpose* that challenges the autoethnographer to write stories that *speak to souls, hearts, and minds*. My hope is that my writings reach the parents of children whose experiences mirror my own. While writing about qualitative research and ethnography, Denzin and Lincoln (2001) describe the type of purpose I see in my autoethnography:

> Qualitative research is an inquiry project, but it is also a moral, allegorical, and therapeutic project. Ethnography is more than the record of human experience. The ethnographer writes tiny moral tales, tales that do more than celebrate cultural difference or bring another culture alive. The researcher's story…will help men and women endure and prevail in the opening years of the 21st century. (p. xiii)

My hope is that my stories will find the souls, hearts, and minds of those who need to read it most, so that they can heal, empathize, act, change, open, enter into dialogue, or even find a space to share their own similar story. This is one reason I chose autoethnography as my methodology. Another reason revolves a more pragmatic choice to the skillset I learned not only in graduate school, but my life prior to my graduate work.

The tasks of the autoethnographer match my training and skills as a former journalist, communication specialist, and writer. Tasks of going to a place intently observing, recording, listening, collecting while there, then returning to another space to write, reflect, and rewrite. These tasks are not so different from my everyday life where an innate curiosity, a curiosity that led to professions involving questioning, causes me to

watch and reflect on life simply as a way of living. Chiseri-Strater and Sunstein (2012) describe this writing:

> Many of us enjoy people-watching, checking out how others talk, dress, behave, and interact. We question the significance of someone's wearing gold, hooped earrings or displaying a dragon tattoo. We wonder how a a certain couple sitting in a restaurant booth can communicate when they don't look each other in the eye. (p. 1)

The difference is the conscious choice to channel the work toward a purpose and into a process to create a research project that becomes public. However, I can't deny the appeal of autoethnography on my heart and mind as it speaks to me and moves me in ways other research does not. I choose autoethnography not only because it is the best method to answer my research question, but because autoethnography is my passion as a researcher, because I have been doing autoethnography all my life, even if I couldn't have articulated it earlier. I might have called it storytelling and looking back I may have been a storyteller much of my life. Ellis (2013) writes of this tug toward knowing autoethnography as more than a method, but a way of living:

> I have been an ethnographer all my life. I also have been interested in peoples' emotions and intentions and how they create meaningful lives and cope with the problems of living…autoethnography felt perfect to me because it combined my interests in ethnography, social psychology of the self and role-taking, subjectivity and emotionality, face-to-face communication and interaction, writing as inquiry and for evocation, storytelling, and my social work orientation toward social justice and giving back to the community. (p. 17)

Ellis described fighting a backlash to the storytelling and imaginative nature of autoethnography by those who ruled through positivism only valuing systematic data collection. But she also describes autoethnography as a *calling*. I too, feel the call.

I feel the call to write an autoethnography that is situated in qualitative research, in which a biographically situated researcher, guided by a critical axiological concern for social justice, creates a performative academic product. The resulting text serves as the autoethnographic product. The product represents writing as inquiry and is a layered, fragmented, impressionistic, mixed-genre of complex images, imaginings, and stories that form an interpretive, autoethnographic narrative that disrupts the traditional, linear, hierarchal notions of research in the academy that Ellis (2013) described.

Ricci (2003) writes about the difficulty of defining autoethnography and the need to forge your own path. I see autoethnography, while dealing with the self and searching for an understanding of self, also as a search for an understanding of other, and often that understanding comes from writing about the self. Ellis (1999) describes this:

> Autoethnography is an autobiographical genre of writing and research that displays multiple layers of consciousness. Back and forth autoethnographers gaze, first through an ethnographic wide-angle lens, focusing outward on social and cultural aspects of their personal experience; then they look inward, exposing a vulnerable self that is moved by and may move through, refract and resist cultural interpretations. Concrete action, dialogue, emotion, embodiment, spirituality, and self-consciousness are featured, appearing as relational and institutional stories impacted by history, and social structure, which themselves are dialectally revealed through actions, feelings, thoughts, and language. (p. 673)

Autoethnography takes the form a text shared with others. This acts to amplify its meanings to a larger audience. McMillan and Price (2009) write, "even as we tell our

own stories, those stories become richer, expanded, potentially connective, as other interact with our narratives…inclusion abounds" (p. 146). In writing autoethnography, I sought to include others in my stories by inviting the reader of my text into a relationship through the text.

Autoethnography and Qualitative Research

Research is conducted in the shadow of the ivory tower, a fact I can neither escape or ignore. I must consider a way of understanding and doing research that considers this context since most undergraduates, graduates, doctoral students, tenure-track, and tenured researchers are all conducting research in this space.

While searching for the right fit underneath the ivory tower's umbrella of labels, one would probably skip the physical, practical, and applied sciences, pass over the professions, and perhaps try to find a space underneath the social sciences, humanities, or arts. However, autoethnography doesn't fall squarely anywhere under the umbrella. Its nature is interdisciplinary, so in theory it becomes a fabric stretched across multiple divisions of the umbrella and being solely representative of none. However, for now, in practice, autoethnography tends to be found in the social sciences, humanities, and the arts, with much of its use in the often overlapping fields of education, cultural studies, and communication. I believe autoethnography has potential to be employed throughout the academy and beyond the academy, but for now is primarily used by qualitative researchers.

To recognize autoethnography as qualitative research does not preclude its use in quantitative work (theoretically), or the use of quantitative work in autoethnography.

Denzin and Lincoln (2011) describe the incorporation of quantitative work into qualitative research "while many qualitative researchers in the postpositivist tradition will use statistical measures, methods, and documents as a way of locating a group of subjects within a larger population, they will seldom report their findings in terms of the kinds of complex statistical measures or methods that quantitative researchers are drawn to" (p. 9). Some scholars seek to apply labels to divisions between qualitative, quantitative, or mixed methods in all research. However, my research does not lend itself toward solely to quantitative work, nor even mixed-methods, because typically research under those labels tend to emphasize monological, reductionist, and positivistic lenses. In my research, I seek what Denzin and Lincoln describe as a *postmodern sensibility* to research writing:

> The use of quantitative, positivist methods and assumptions has been rejected by a new generation of qualitative researchers who are attached to poststructural or postmodern sensibilities. These researchers argue that positivist methods are but one way of telling a story about society or the social world. They may be no better or no worse than any other method; they just tell a different kind of story….Many members of the critical theory, constructivist, poststructural, and postmodern schools of thought reject positivist and postpositivist criteria when evaluating their own work….that positivist and postpositivist research reproduces only a certain kind of science, a science that silences too many voices. (p. 9)

I locate myself and my research here in the critical, constructivist, postmodern schools of thought described by Denzin and Lincoln. I am situating myself clearly in the qualitative field. Some scholars may be lured into the murky field of mixed methods, which Denzin and Lincoln (2011) describe as a label in the "methodological hierarchy" which places quantitative at the top and qualitative at the bottom (p. 7) leaving mixed

methods as a compromise left over from the "paradigm wars" of the 1980s. Denzin and Lincoln (2011) cite Howe in highlighting the mixed method divide of exploration and confirmation that renders mixed methods incompatible with truly critical qualitative research writing:

> The traditional mixed methods movement takes qualitative methods out of their natural home within the interpretive framework…this movement excludes stakeholders from dialogue and active participation in the research process…and decreases the likelihood that previously silenced voices will be heard. (p. 7)

Critical communication scholars Nakayama and Halualani (2010) warn against "academic obsession for boundary delineation and identification of positions" (p. 10). Denzin and Lincoln (2011) describe the problem of strict boundaries: "inquiry is cut off from politics. Biography and history recede into the background. Technological rationality prevails" (p. 2). I have no desire to wage war against those who employ mixed methods or evidence-based inquiry, however I do not want to be forced into accepting that paradigm and fear the threat I've experienced so many times before of being asked to fit into a box given to me by someone higher in the academic food-chain hierarchy.

I define my research as qualitative research. I interchange the use of the terms qualitative research/methodology with interpretive research/methodology, or even toggle between qualitative paradigm and interpretive paradigm. Both qualitative and interpretive are broad terms that mean many different things to different people. For my research, these two terms are the same: qualitative research is interpretive and interpretive is qualitative. These two terms serve as an umbrella of sorts for all that comes after and as a

way to differentiate my research from quantitative or mixed methods approaches. However, in doing so I want to avoid insisting that there is any monological way of doing qualitative work or that researchers universally agree on how to conduct interpretive research.

I draw on Marshall and Rossman's (2011, p. 2) four stances of qualitative research:

> …enacted in natural settings; draws on multiple methods that respect the humanity of the participants in the study; focuses on context; is emergent and evolving; is fundamentally interpretive…qualitative researchers…view social worlds as holistic and complex, engage in systematic reflections on the conduct of the research, remain sensitive to their own biographies/social identities and how these shape the study/reflexive, and rely on complex reasoning that moves dialectically between deduction and induction. (p. 2)

While I am drawn, like many other qualitative researchers, to the complexities of life that can't be explained or known through quantitative analysis and in particular analysis by outsiders, I'm most interested in the meanings that participants attribute to social interactions. I'm opposed to the binary world of narrow dichotomies that are often forced upon society as objective reality. I'm interested in the meanings created by participants rather than the conclusions drawn by quantitative so-called objective researchers. I believe the world is one of interpretations, my own and others, all layered together. I'm drawn to natural settings rather than laboratories, the lived experiences of people and how they and I and we make meaning from those experiences.

As a qualitative researcher I do not shy away from writing about and with emotion. I embrace the *I* and all it entails. I believe in a socially, historically, and biographically situated researcher as a way to counteract the hegemony of traditional so-

called *scientific* research that reifies the notion of *objective* research. To me, objectivity is simply a way to hide power relations in the researcher/subject binary.

Qualitative inquiry requires a researcher to become familiar with a wide range of theories and methods, so that the researcher's tool bag is chockfull of choices to draw from in the unfolding act of research. By drawing enough of these threads together, the support for research is created without becoming so concrete as to risk slippage back into traditional Western positivism or what Kincheloe (2008) named FIDUROD: formal, intractable, decontextualized, universalistic, reductionistic, and one-dimensional (p. 21-23). FIDUROD defines itself epistemologically against what it is not. I will summarize Kincheloe's concept of FIDUROD below to illustrate the critical scaffolding for my research.

A critical framework is not formal: it avoids checklists and rigid methodologies, and instead privileges switching, changing, improvising as appropriate due to rethinking as the research act unfolds. A critical framework is not intractable: the empirical world is not static and unchanging, but instead evolving, chaotic, complex, changing, just like the researcher and the researched. A critical framework is not decontextualized: isolating research from its contexts produces invalid knowledge, instead research should acknowledge that a wide variety of situational variables ranging from the historical to political to economic to cultural to social to ideological impact the research, researcher, and researched in a way that must be accounted for in the meaning making process of knowledge construction. A critical framework is not universalistic: knowledge construction should not assume validity across time and space, instead emphasizing local

and situational knowledges. A critical framework is not reductionistic: you can't create valid knowledge through measurement alone, but instead, combine quantitative results pluralistically with a multitude of lenses through which to view the issue. A critical framework is not one-dimensional: it does not favor the formal, positivist view that correct research methodology leads to truth, but instead honors multi-perspectival ways of ontology.

Kincheloe, McLaren, and Steinberg (2011) in an attempt they described as *risky business* because of critical theory's variant meanings, outlined a set of *basic assumptions* to which most criticalists would ascribe (p. 164). I briefly outline those assumptions here to describe the common threads that entangle various theoretical and methodological tools I employed. In doing so, I do not attempt to define critical theory or any of the various theories, methods, and pedagogies I've studied, but instead I seek the common threads I can weave together as supports in the theoretical embrace and methodological employment of my research.

Here I briefly outline in condensed fashion those assumptions (Kincheloe, McLaren & Steinberg, 2011) to illustrate how critical theories can be connected: all thought stems from social/historical power relations; facts are inseparable from values and ideology; capitalism/social relations mediate the changing relationship between subject/object or signifier/signified; language matters; privilege/oppression operate through hegemony; oppression connects across isms; and mainstream research unwittingly reproduces oppression. To that list, I would add the characteristics I discussed in chapter two: all knowledge is contested; knowledge must be contextualized;

the production and constraint of knowledge work must be addressed. The most common thread between them all is the fundamental string of power on which all critical frames focus — how does power relate to knowledge, whose interests are served, who benefits? These questions assume an unequal society based on a hierarchy in need of leveling toward a more equitable existence for all. There is a utopian vision in critical theories expressed in the hope and optimism for a better world. Bronner (2011) describes this critical vision of utopia:

> Scarcity is overcome, and individuals cease to view one another in instrumental terms. People are placed before profits, work turns into play, and a new sensibility takes shape that is almost biologically repulsed by cruelty, exploitation, and violence…. Time is no longer conceived in linear terms but rather, following nature, as an internal circular process. (p. 71)

If critical theory began with a purpose to unveil repression in the hope of transforming society, that liberating hope may have been lost after the atrocities of World War II that saw the Frankfurt School exiled to the United States trying to reconcile the wake of Nagasaki, Hiroshima, and Auschwitz during a post-war capitalistic boom. Critical theory post-WWII took off in America in the counter-culture movement of the 1960s, but according to Bronner (2011), didn't become a part of the academy until the 1980s (p. 100) when critical legal studies, critical race theory, critical gender studies and other groups emerged that began to question systems, master narratives, the Western canon, and popular culture (p. 101). Bronner describes this period from the 1980s through today as the time critical theory lost its transformative focus and suggests critical theory has lost the ability to change the world:

> New proposals have not been forthcoming for dealing with imperialistic exploits, economic contradictions, the state, mass media, and the character of resistance in modern society… [critical theory] now lacks an understanding of power and, as a consequence, the ability to confront the imbalance of power. (p. 101)

The nearly 10 years, since Bronner penned those words, may have proven him right, as society witnessed the rise of Trumpism (Lucas & Bond, 2019), the rise of authoritarianism around the world, and greater wealth inequality (Howell & Elliott, 2018). It's hard to be optimistic. I see the varied tools of critical theory as a means to address the ills of the world, not only in this research, but in the future. Perhaps I'm naive, but I envision a reinvigorated critical theory allowing scholars, once broken free from the formal moorings of traditional academic expectations of form and format, to create the new projects that could lead society toward a reversal of Bronner's pessimistic proclamation and toward a world oriented to social justice instead.

Bronner (2011) called for academic products grounded in hermeneutics, performance, digital presentation, open and free access, employing democratic research techniques such as crowd-sourcing, and infused with a pluralism and multiplicity that not only confront power, but dismantle it — all toward imagining and ushering in a new world based on the ideals of social justice. Though I realize my research does not meet all of those goals, it is my sincere hope that the research did in some small way help imagine a new world, especially for those families with children experiencing disability who feel stuck in compulsory public schooling. Perhaps the autoethnography I created, could usher in a new world for even one family who reads the text.

It is time to answer Denzin's (2011) challenge to my generation of scholars to "articulate its epistemological, methodological, and ethical stance toward critical inquiry" (p. x). For me this means donning the mask of Argus embodied, revealed, self-reflexive, and yet fluid in the field of qualitative research, inviting others into the space of critical inquiry at the borders, working with marginalized voices, on the shifting grounds of a complex and chaotic pluralverse (Kincheloe, 2008), using an ever-deepening bag of theoretical and methodological tools to explore in a postmodern fashion the social construction of self and the world I encounter. This is the spirit I wish to engage in as a scholar. My role in the academy is not to simply produce scholarship. My role is to make the world a better place through social justice action in the world based on my personal praxis, or action inspired or caused by my scholarship and teaching.

I seek to cross disciplinary borders, to work in the liminal spaces of the margins and borderlands (Elenes, 1997), and wish to disrupt, rupture, and create new spaces at the complex intersections of disability, race, sexuality, gender, class, ethnicity, and other sites of identity, culture, marginalization, and power. The embrace of the political toward a hope for transformation makes it an uncomfortable place for many scholars schooled in the positivistic, monological, reductionist, and disciplinary academic world that often seeks to find one truth, one fact, one explanation of the world through a thin veil of so-called objective research. If qualitative scholars won't fight for social justice, take a political stand, work for liberation, enter spaces of love, forgiveness, and hope, explore spaces of spirit, emotion, and myth to unveil power and confront it — who will? If qualitative scholars won't envision the world anew, the academy is left with quantitative

dicing of the current world over and over, serving the centers, commodifying research for grantees or corporations, and reifying existing power structures. It is my clear intention to embrace the political nature of my research as a path toward unveiling power, inequity, and injustice in a sincere hope for change.

I firmly plant my roots in the field of qualitative inquiry, not in the shadows, but in the bright, healing, growth-inspiring light of Freire, Kincheloe, Hurston, Britzman, Siebers, Denzin, Lincoln, Berry, Goodall, Conquergood, Ellis, Bochner, and Poulos, all scholars that not only inspired me, but challenged me as I read their work.

Culture

> A society's culture consists of whatever it is one has to know or believe in order to operate in a manner acceptable to its members. Culture is not a material phenomenon; it does not consist of things, people, behavior, or emotions. It is rather an organization of these things. (Goodenough, 1966, p. 167)

Ethnographers employing Goodenough's definition of culture may remain vulnerable to creating a monolithic image of culture that becomes a hegemonic tool to reify what is acceptable to maintain the status quo and power hierarchies as they exist in the culture at that moment. This becomes a caution of ethnographic inquiry — the danger of slipping into positivism and formalism as a butterfly catcher who thinks by netting and pinning the insect to the board, culture has been captured.

Raymond Williams (1982) noted the complexity of culture and difficulty of defining culture. Chiseri-Strater and Sunstein (2012) call the effort of defining culture "slippery" noting, "anthropologists have tried to define what culture is for as long as

they've been thinking about it, and they have developed contrasting definitions" (p. 3). Chiseri-Strater and Sunstein mine definitions of culture from Benedict, Goodenough, Myerhoff, and Geertz to define culture for their text *Fieldwork: Reading and Writing Research* as, "an invisible web of behaviors, patterns, rules, and rituals of a group of people who have contact with one another and share a common language." This definition worked well with my Masters thesis work exploring disability culture.

I observed others during my own immersion into disability cultural events and by living, interviewing, and writing about two men who experienced disability as blindness, *the behaviors, patterns, rules, and rituals* of the so-called others, their contact with one another, and the languages they used. I took photographs, videos, collected artifacts, recorded voices, and music, I wrote notes and poems, I detailed my observations in extensive notebooks, I journaled, I transcribed, I read, I watched, I asked, I participated, I lived, ate, and breathed what I saw as a separate culture that could be observed and written about as valid research. Adopting Powdermaker's (cited in Chiseri-Strater & Sunstein, 2012) outsider and insider stances, I weaved in and out of disability culture realizing at the end of my research that I was not an objective scholar studying the other, but had unknowingly belonged to disability culture the entire time. Powdermaker describes this process of discovery:

> Long before I ever heard of anthropology, I was being conditioned for the role of stepping in and out of society. It was part of my growing up process to question the traditional values and norms of the family and to experiment with behavior patterns and ideologies. This is not an uncommon process of finding oneself. (p. 1)

This discovery of self can be a strength of the ethnographic process. I went into my ethnographic study of disability to find the other, to understand disability culture, and therefore understand my son. I came out not with a better understanding of the other, but of myself.

Examining Chiseri-Strater and Sunstein's definition of culture in relation to my autoethnographic inquiry, I begin to read it differently. I am no longer uncovering the hidden webs that describe the culture, but unveiling the hidden webs that reveal the power structures that maintain certain constructions of that culture. For example, the autoethnographic stories I've written about in the past of our inclusion and exclusion experiences in public schools reveal an invisible web, but not one that represents the culture itself. Instead, the invisible web represents a set of behaviors, patterns, rules and rituals that seek to maintain the status quo that is the cultural representation. My autoethnographic inquiry reveals invisible webs of new meanings and new readings of that culture that cut across typical understandings of it. At the same time, my autoethnographic inquiry reveals new webs of meaning making that redefine, re-envision, re-imagine what that particular culture means, and creates new cultural understandings and representations. As a researcher, I have to return to Geertz (1973) to thicken my description of culture as "our constructions of other people's constructions" (p. 9). An ethnographer or autoethnographer goes into the field with a tool bag chock-full of theory and method from which to draw appropriately in the unfolding act of research as it occurs in the field. The researcher uses any number of tools to access and collect data from interviews to surveys to observation to recording to measuring to participating to

journaling and beyond, but always writes the researcher's position and process as part of the academic product.

Intersubjectivity

Autoethnography is a relational methodology that results in a textual product that initiates a relation between writer and reader. The researcher is writing the subjective reality of the researcher's own experience into a narrative that is read by another human, who is reading through the lens of their own subjective reality of personal experience, and now those separate realities have entered into relation through the experiencing the common text. This relation could not happen without some degree of shared understanding, an understanding most scholars refer to as intersubjectivity. In their 2008 book *Intersubjectivity: What Makes us Human?*, Zlatev, Racine, Sinha, and Itkonen describe the concept:

> In the simplest terms, intersubjectivity is understood as the sharing of experiential content (e.g. feelings, perceptions, thoughts, meanings) among a plurality of subjects…the human mind is quintessentially a shared mind and that intersubjectivity is at the heart of what makes us human. (p. 2)

In one way, intersubjectivity allows research to be known to the reader, because it is simply a way to make and share some common meaning of the world around us. However, I disagree the notion that a shared mind makes us human (Zlatev et al., 2008), and in fact would argue the opposite, that it is our individuality that make us human, and intersubjectivity becomes one tool we can use to make sense of the world. Those intersubjective meanings, however, are often contested and rarely agreed upon (Chiu,

Gelfand, Yamagishi, Shteynberg, & Wan, 2010), especially when involving a topic such as disability, in which the dominant discourses are often mediated by those in power and those who are not or have not experienced the subjectivity of the marginalized group (Owens, 2014). Chiu et al. (2010), in their study of intersubjectivity and culture, highlight that even when we can come to some intersubjective agreement that a particular culture exists, the beliefs, behaviors, and values inside that culture are not monolithic and vary tremendously among the culture's members, according to context, yet there is a pressure to conform to the intersubjective reality. Chiu et al. (2010) write:

> The values and beliefs that are perceived to be widespread in a culture are not necessarily the same values and beliefs that people in the culture endorse and vice versa. Moreover, individuals may act on behalf of the intersubjective reality even more than they act on their personal values and beliefs. (p. 483)

In this autoethnography, I write about disability culture and homeschooling/unschooling culture. I do not attempt to define culture, only describe. Disability culture for example, any culture really, is composed of connected multiple meanings along similar threads, woven together by time in a connection impossible to disentangle from one another. These threads form a web. Some threads are thin, some are thick, not all threads can be seen or known or understood, no one thread defines culture alone, and yet the appearance of a whole web also does not define that culture alone. Kincheloe (2008, 2005, 2001) described such web as a metaphor for reality that connects the researcher's location or position in a complex and chaotic space that is never static and always moving as the researcher moves through time. The threads of Kincheloe's

web metaphor locate the research in historical, social, political, and other intersubjective positions allowing the researcher to articulate influences that impact the study. From this perspective culture cannot be defined, only described. Culture is fluid, chaotic, and complex. My aims as a researcher doing autoethnography become defined against what they are not: not to define, only describe; not to explicate, only explore; not to know, only interpret; not to tell, only show; and not to understand, only perform.

Given the difficulty of coming to any real intersubjective meaning outside the individual context of one's own experience, how does a researcher address the contradiction? Writing about fieldworking and the reading/writing process, Chiseri-Strater and Sunstein (2012) address the issue's importance writing: "What you see is affected by who you are. Your education, geography, family history, personal experiences, race, gender, or nationality can influence the way you do research" (p. 111). The two ethnographers describe addressing intersubjectivity as a method of "connecting as many different perspectives on the same data as possible" (p. 111) as a form of objectivity that might answer social science critics who might object to a lack of objective data. But how does one *connect* this data when the data is written from the perspective of one researcher? Early critics of autoethnography (Coffey, 1999; Atkinson, 1997) describe the texts pejoratively as "self-indulgent, narcissistic, introspective, individualized" (Mendéz, 2013) pointing to this lack of objectivity as a reason autoethnography should not be part of social science. Chiseri-Strater & Sunstein describe a process like Richardson's (2000; as cited in Kincheloe, 2001) crystal metaphor, that challenges the researcher to look not through a magnifying glass in only one way, but

instead through fractured, multifaceted lenses. This action involves not only turning these multiple lenses out to the world, but into the mirror looking at ourselves as researchers as we weave our data through self-analysis in an act of reflexivity to reveal to the reader and ourselves the multiple historical, physical, cultural, economic, political, ideological, and social positions we chose and that are thrust upon us without our consent. Chiseri-Strater and Sunstein (2012) call for researchers to situate themselves with descriptions of position, subjectivities, and language in a process that becomes writing what they name as *twin tales* or "your informants' perspectives and your own perspective on the research process" (p. 361). While in ethnography you have traditional subjects of your research that are informants, in autoethnography the researcher is, in essence the informant. I believe the method of writing twin tales is also useful in autoethnography as a way to address intersubjectivity.

Toyosaki and Pensoneau-Conway (2013) use the metaphor of a thread that describes the nature of autoethnography as an individual experience in a micro context that connects to other threads in the large macro context. They write of autoethnography and intersubjectivity:

> We cannot comprehend our identity without accounting for how identity is enmeshed in a context, and more specifically, in the context of embodied social relationships…We are intersubjective beings…Thus, autoethnographers are already social authors. They rely on the convention of the intersubjective, social practice of narrativity in creating their understandings of their lived experiences. (Toyosaki & Pensoneau-Conway, 2013, p. 565)

Toyosaki and Pensoneau-Conway (2013) further elaborate on threads between the macro social world and the micro world of the autoethnographer by connecting autoethnography and social justice describing the work of the autoethnographer being a "micro-social labor against social injustice" (p. 562) and a "thread that weaves together with others to actualize social change" (p. 562). I see my research doing both, connecting my micro experiences that I write into an autoethnography with the greater intersubjective contexts of the reader, and hopefully also inviting the reader into a collaborative praxis of social justice where the text of my micro-experiences might relate to the intersubjective experience of another leading to some transformation action in that reader's life. Toyosaki and Pensoneau-Conway (2013) reflect that hope writing:

> Doing autoethnography is inherently and always already a labor of social theories; therefore, autoethnographers as intersubjective, social, and dialogical selves possess potential in rendering a critical impetus to promote social justice. (p. 565).

I'm choosing autoethnography as method because, like Toyosaki and Pensoneau-Conway (2013) I both see the potential for and have the goal of encouraging social justice action. But how do I address intersubjectivity? I first acknowledge that my representations of the world, disability, whiteness, privilege, marginalization, inclusion and exclusion, deschooling/homeschooling/unschooling using a method of autoethnography are constructions of the micro contexts of my individual experience viewed through my own lenses, rather than some universal, subjective truth. And as I write I use Richardson's (2000) multiple, fractured lenses to examine the types of stories I'm choosing to narrate versus leave out, so that the autoethnography is not as some

critics might say, indulgent or narcissistic, but instead examines the important historical, physical, cultural, economic, political, ideological, and social positions of the researcher and researcher's story. Lastly, I use the twin tales process described by Chiseri-Strater and Sunstein (2012) to write my own stories positioning age, gender, class, race, ability, privilege, and other often unexamined factors, through narratives of my life history and personal experiences that weave through the autoethnography, connecting the subjective experience of the writer to the intersubjective experience of the reader.

Situating the Research

Though all people live out life in an empirical world, coming to agreement on a description, interpretation, or any common meaning of that world seems an impossible task. However, I would add the qualification that my personal interpretation and description of the empirical world is just that — my meaning. I offer up my understanding only as a way to communicate with others in the hope of achieving some small progress toward transformation in regard to social justice issues. I do not offer this understanding as truth, nor a rigid ideology. To me, there is no such thing as a universal truth, nor objective stance — all understandings, interpretations, and meaning-making activities, including research, are inherently political and value-laden. However, I understand that there are those positivistic, so-called *scientific* researchers operating in strict disciplinary boxes, primarily with monological quantitative paradigms, fueled by neoconservative and neoliberal calls for evidenced-based work, who certainly would offer a different world view. Finding my location is as much an effort to set myself apart — from those traditional, patriarchal, Eurocentric, elitist scientists who typically reside in

the natural sciences, but increasingly are found in the social sciences, humanities, and perhaps even the arts, touting their mixed methods as a cloak for quasi-quantitative research — as it is to articulate my own position as a philosophical researcher working along the blurry lines between the humanities and social sciences in a qualitative paradigm as an interdisciplinary scholar crossing borders between communication, cultural studies, and education in critical social-justice inquiry using autoethnography as a primary practice to change the world.

My research agenda is anchored in the goal of social justice transformation. My vision of this future as an academic researcher and pedagogue places me working to answer Denzin & Lincoln's (2011) call to create new spaces, new discourses, and new fields of inquiry where new forms of academic products flourish.

To understand my location is to begin with my ontological position as one bracket to my own subjectivity with the other bracket being my epistemological position. By articulating the two, I hope to offer an understanding of my philosophical consciousness that situates my work. To begin, I offer my historical location in the following brief chronology.

For more than 30 years, I've worked as a communication practitioner from journalism to public relations to freelance work in video, audio, and print. Over the past 20 years, I have worked both on a paid and volunteer basis to teach age groups ranging from pre-school to adult-learners, but primarily have taught communication courses to undergraduates at a mid-size comprehensive university in the south. I believe by working inside the academy as a researcher and a pedagogue, I can create the most impact on

social justice issues. A focus of my research and pedagogy has been and remains issues surrounding disability, and in particular, around people experiencing Down syndrome. I am not only an advocate who volunteers locally, regionally, and statewide with and on various disability support, political, and action organizations, but I am a parent of a child who experiences Down syndrome, and son/grandson to relatives who have experienced mental illness. I offer this chronology as a brief explanation of the driving passion behind the political nature of my pedagogy and research. Beyond reflexivity on my part as an academic, my past experiences and current circumstances affect my axiological stance. I do not hide my values as a researcher, nor what motivates what I choose to research, nor what or how I choose to teach. I embrace my role as a critical scholar who takes a liberationist philosophical approach toward all work in the academy and unabashedly states the goal of emancipation, transformation, and action toward social justice for those at the margins where I conduct my work. Conquergood (1991) called for an excavation of the political in our research process and points out that "logical empiricists are dedicated to the eviction of politics from science" (p. 179), while, "critical theorists, on the other hand, are committed to the excavation of the political underpinnings of all modes of representation, including the scientific." As a researcher employing critical theory, I attempt to unveil my own politics through reflexive practices.

I am just starting to understand, for now, the ontological nature of social justice work as a multilayered rope of tensions among strands of justice, injustice, power, powerlessness, hegemony, resistance, liberation, oppression, despair, and hope. This tension between empirical reality, and the vision of how that world could or should be,

will always leave me as an incomplete scholar with my praxis focused not on fixing the world, but on supporting the understanding of its construction, my place in that construction, and the communication of those understandings in hopes of transforming the world toward a more socially just existence. Thus, situated as a scholar in a world in need of social justice transformation, I must take an axiological stance. What do I value? My answer is social justice transformation. Thus, at this point in my never-ending journey of becoming a scholar, I feel compelled to declare to the world my understanding of myself as scholar, of my role as researcher, and to stake a claim to a position as a scholar from which to situate my work. Since I've linked my understanding of myself as a scholar to social justice, my axiological stance is centered specifically on how I articulate my aims.

I am drawn to interdisciplinary work. I am certainly a scholar working to bring my work out of the dark shadows of the towers to spaces beyond the often-narrow confines of so-called acceptable research in the academy. Traditionally, the academy focuses on strict disciplinary boxes and enforces those borders by limiting courses students can take outside their department, keeping professors teaching in their disciplines, and by rewarding those who publish in field-specific publications. I bring an undergraduate background in English and writing that infuses my work with the importance of storytelling. My master's degree in liberal studies reminds me of the eclectic nature of inquiry and the open spaces of learning possibility when one crosses borders between the arts, sciences, and humanities. My background teaching communication combined with my graduate work in communication studies highlights

communicative practices as the vehicle by which identity, culture, community, and the relationships between them are transmitted. My current work in cultural studies reminds me to seek the hidden, question power, and to work for social justice. With a finger in each field, I feel no allegiance to one over the other, but instead see myself moving in and out of each field as needed, drawing what is required for the task at hand. In choosing autoethnography as method, I choose to disrupt what is typically expected in the academy not just to be disruptive, but because all my academic experiences prior to this moment led me here to a space Conquergood (1991) described as, "mov[ing] performance from hermeneutics to a form of scholarly representation" (p. 191). However, he warns, "that move strikes at the heart of academic politics and issues of scholarly authority" (p. 191). Though I can situate myself as a researcher, I would like to borrow a concept from Villaverde (2010) to acknowledge the fragile ground researchers tread upon, which she named a *faultline*:

> why faultline and a critical one at that? a faultline is a precarious space, on the verge of… something… of rupture. when something unsettles the core it slowly impacts, in a ripple effect, the very ground we stand on. one is decentered, caused to shift, regain footing. we may see clearer into the newly revealed space recognizing all sorts of paths… ultimately new fissures arise and we are able to theorize more concrete possibilities… [capitalization as appears in blog] (Villaverde, 2010)

No matter what field a researcher names, whether cultural studies or communication studies or another, that field is not steady. The ground underneath is constantly moving, constantly shifting, with each scholar's contributions to the field. To recognize this helps me understand shifting and unpredictable way of creating new spaces

from which to conduct research. It's in the lacuna, the liminal, the pushed-up fractured earth that one can find a subject or a text. Sasaki (2002) called this a "third-space or borderland" where "we have the greatest opportunity to hear both the unspoken and unspeakable knowledges" (p. 44). This third-space is the uncomfortable dialogue of otherness and privilege that I must continue to forefront, which is ripe with the reinforcement not only of dichotomies, but with maintaining current power structures.

I am not a complete scholar, nor will I ever be. I sometimes long for a positivist understanding of what a scholar is, and for reaching that objective first moment when I have become said scholar, and from that point forward existing in the indisputable truth of the unflinching knowledge that I am valid, reliable, and permanently a part of a pantheon of disembodied minds that articulate the world as bricks of gold upon which the foundations of existence are built higher, ever higher through noble quests from, retreats to, and life inside the ivory tower. But that longing is a mythical dream from which I must escape.

I am and will always be in a process of becoming. I link my existence as a scholar to the cause of social justice; I will not be complete, I cannot be complete, until the liberating moment when I, with the entire world, meet at the end of Dr. Martin Luther King Jr.'s moral arc where it transforms from a hope to a realization. Until that day, I must continue listening, storying, and sharing the narratives that form the core of my research efforts.

The goal is ultimately not to know an object or subject, but to learn from the subject or the object — to realize that there is always something of the researcher in the

interpretation. I cannot escape my preconceptions, my prejudices, the political nature of any research act — I can only hope to articulate those contexts and attempt to anticipate the impact upon the process of research.

Storytelling

> As I look back…I see books, thoughts, even lines of poetry that intrigued me to such an extent that they became part of my consciousness. And though the ideas did not seem particularly connected at the time, they eventually gave rise to this project and have shaped it and given it meaning. If I had to discuss the ideas and name them, I would call them *continuance* — the remembrance of times, places, and people; the knowing of those times, places, and people through imaginative acts; and finally, the going on, the telling of the stories. (Cobb, 2000, p. xv)

I live a storied life. I always have. I think I always will. Like Cobb (2000), who in her role as an ethnographer collecting and retelling stories of her Chickasaw heritage became a part of the very continuance of lives she studied, my consciousness as a scholar becomes intertwined with what I study in my own imaginative acts and the *going on* of telling stories. In Cobb's (2000) listening and telling of stories (p. 127), the lines begin to blur between the personal and what some people would label separately *academic*. Cobb notes this blurring by labeling her work a "scholarly, historical narrative," but also admitting, "there is a need to touch, and this book is an attempt to know my grandma better, to reach through time, to listen to and touch the past" (p. xvii). I too, have often felt a bipolar pull between the personal and the academic where I feel compelled to hide what drives me to research, so that I appear more academic. Cobb embraces both, "in my search though archives for documents, data, pictures, and memorabilia, I search for Grandma" (p. xvii). In my own research, I wish to drop the false pretense and fully

embrace a storied life as a scholar. I wish to blur the lines between the personal and academic. I want to tangle the knower and the known. No matter how often I stray from living a storied life, I inevitably return to it. It's innate.

I wrote my first bylined story in the fourth-grade at my public elementary school for Mrs. Shepard. She had thick cat-eye glasses, a beehive hairdo, and a wardrobe mix of velour and polyester that screamed '60s even though it was the 1980s. Our curriculum revolved around fraction worksheets, spelling worksheets, science worksheets, and plaster-of-paris projects of hands praying or baby Jesus. However, she did make us write poems or stories on a daily basis and that is what I loved most. On the last day of the school year, she gave each class member a mimeographed, folded and stapled-in-the-middle yearbook of our written work, all interspersed with washed-out, black-and-white photos that seemed more ghostly shells than kids. On the bus ride home, I flipped through the couplets about dogs or cats, paragraphs about hating little brothers or sisters, and there at the very back I found two full pages of one of my stories. No one else got two pages. I felt special. No one else got more than a paragraph. My story detailed the action-packed adventure of William Shakespeare coming back to life in modern times. I read it over and over. It wasn't just the symbolic nature of seeing my name in print for the first time that mattered, although I loved it, and still to this day, I get giddy about a byline. It was the first time I thought of myself as a writer, as a storyteller…it was the first time someone made a space for my voice to be heard. That one event began my storied life, a life in which I represent in words, photographs, and video my interpretations of the lived experience of self and others. In the world of work, I became a journalist, a public

relations professional, and eventually a teacher/scholar. In all three professions, I had unique opportunities of storying life through various lenses from the so-called *objective* view of a reporter to the *spin* of public relations work to the self-reflexive knowledge work of a qualitative, critical scholar. Outside of work, I storied my life in journals, short stories, poetry, and through film/digital storytelling. I don't draw distinct lines between ethnography and autoethnography, preferring to describe myself as a combination of both — perhaps an auto|ethnographer. I see my work as Cobb described her work as an ethnographer, "adding a new thread to the stories that already exist" (p. 16). Cobb critically acknowledged her own historical and social position in her work. She stated, "no research is free from the ideological interpretation of the researcher" (p. 17). I agree. Whether innate or learned, I have a need to story. And I would like to think I have an ability honed over the more than 30 years of storying experience since my first byline at age 10 in Mrs. Shepard's class. However, I wish to temper the need and ability to story with a responsibility as a critical researcher to unveil, as much as possible, my own process, which is certainly not neutral, so to acknowledge my own historical and social position. Outside the privileged centers where mainstream voices rise clear and loud, the marginal spaces where silenced voices rise are often blurry spaces at best. Making openings for the continuance of silenced stories in this blurry space is where I wish to locate myself as a researcher enacting a storied autoethnographic life.

Ethical Considerations

There are pragmatic ethical considerations for the methodology of this study and simple techniques to address them. To honor the privacy of those lives that intersect my

own stories, I use not only fictitious names for people throughout, but also fictitious public school names with the exception of Appalachian State University where I've worked for the past 21 years.

I will not use fictitious names for my immediate family members. My family has been the subject of other graduate research not by me and thus, have experience with consenting to have our stories and the stories of our children a part of a research project. I see no difference in our decision as parents to consent to research for an outside researcher, as to consenting for my own autoethnographic research. We as a family are committed to creating spaces for the often silenced voices of families like ours and we firmly believe that sharing our stories is an act of social justice that has potential to transform lives for the better. I say *we* because for my family this has been a dialogue. I gained prior and process consent throughout this process from my spouse and from Liam for my representations of our family stories. My wife, Janet, not only shares my belief in the importance of telling our unschooling stories, she is my editor and always is the first reader and first critic of all my work. She also had the choice to delete any parts of these narratives. We have considerable experience in the process because my Master's thesis was also ethnographic research and detailed the stories of our family. As she had the chance to read and edit out any parts of the narrative about her or Kenyon and Liam that she didn't feel comfortable with. I do not believe it is necessary to go as far as nom de plume. I believe a pseudonym for the author of the research is often confusing to the reader and not necessary, unless the autoethnographic account puts the author or others at risk. That is not the case here.

My children are already public figures. Kenyon less so than Liam, but Kenyon may have one up on his older brother because his photo twice has been on a national magazine, and in one of those instances he was the subject of an extensive cover story. Both Liam and Kenyon were part of the research for my Master's thesis. Kenyon was part of a pilot study in distance service delivery at the J. Iverson Riddle Center. Kenyon is part of an ongoing genetic research study at Duke University.

Partially because of the visible nature of Kenyon's experience of disability, he is perhaps more well-known by the public. Kenyon developed a love for flat-foot dancing early and began competing at music festivals and won several ribbons including two first-place ribbons in youth dance. Across social media and YouTube there are videos and photos of Keyon in these dance competitions. The magazine *The Bluegrass Standard* featured Kenyon on the cover and in a 5-page story inside detailing Keyon as perhaps the most well-known fan in bluegrass. He may be well known because of his visibility as a person experiencing disability — his body, his face, his movements, his verbalizations, his mobility chair all make him more visible than perhaps the average bluegrass fan. He is in front of people in the bluegrass world, because of his brother's rise as an up-and-coming bluegrass and Americana musician. Liam has played more than 300 shows over the past five years as both a solo artist and the lead/front performer for the band Cane Mill Road. And Kenyon has been there for almost every show, usually sitting on the front row or just off stage and always working the CD/merchandise table after the show interacting with the fans. Kenyon is just as much the face of the band as Liam, and though not as well-known as his brother, he is definitely a part of the current national

bluegrass scene. At the 2019, International Bluegrass Music Association (IBMA) conference we saw Kenyon's public figure status grow, especially after the cover story in *The Bluegrass Standard*, as fans and industry folks asked to take selfies with him for social media.

As for Liam, he is definitely a public figure. His first appearance in print was an article in *Cybergrass* announcing a scholarship he won when he was age 10. Since that time Liam's name and face have appeared on the covers of countless newspapers from our hometown to Argentina. Though his performances fronting his band Cane Mill Road have appeared on national PBS television twice, and will for a third time in October of 2019 on David Holt's *State of Music*, his largest viewing audience was during a performance in Argentina during *Iguazú en Concierto*, which aired live to millions across South America ("Iguazú en Concierto 2019," n.d.). The 9-day trip in 2015 to Argentina to represent the United States at the world music festival for children, also resulted in the band being featured in local, regional, and national media regarding the cultural exchange. The band has appeared on half a dozen other television shows. On live radio, Liam and the band have been featured on national NPR programs twice and conducted dozens of interviews on stations across the United States. Liam and band first charted on Billboard in 2017 with the release of their first album *Five Speed*. Both the subsequent 2018 release of the sophomore album *Gap to Gap* and the 2019 album *Let's All Do Some Living* resulted in Billboard charting, including a peak at No. 2 on the Bluegrass Albums chart and a total of 12 weeks charting. Liam and his band have performed at some of the largest and most iconic festivals in bluegrass and Americana music from MerleFest to

Grey Fox to Wide Open Bluegrass. They have been featured in all the major bluegrass magazines, as well as *No Depression,* the leading journal of roots music.

Liam has co-written a book with bluegrass legend Pete Wernick and had essays published in Suzy Lawson's (2019) book *Singing at the Clothesline*. Liam twice has presented on panels/workshops at the largest music industry conference in the world for bluegrass - IBMA. And three times been nominated for IBMA Momentum awards, which recognize up-and-coming talent in the industry under the age of 30. Liam produced and sound engineered/mixed Cane Mill Road's last album and co-produced an album with 2-time GRAMMY winner Cathy Fink. Liam wrote the score for two movie trailers and for a regional TV show *Life in the Carolinas*. Liam serves as spokesperson for the band and has been interviewed countless times for magazine, newspaper, web, radio, podcast, newsletter, and documentary film content. Countless videos of both Liam and the band exist on YouTube, primarily because he performs in public and people post a lot of what they see at festivals on social media. At least one Liam Purcell Facebook fan group exists and there is another on Instagram.

At age 15, Liam became the youngest Wernick Method (music) teacher ever certified. Since that time, Liam has taught hundreds of adult and child learners at workshops and music camps. Liam learned to play music in a program called J.A.M. (Junior Appalachian Musicians) and since has become an ambassador for the program speaking about the experience in workshops, media/press, and to school groups. Liam has guest lectured twice in college classes (not mine, nor Janet's) and performed a dozen times in other college classes. Kenyon also has guest taught in Janet's classes four times.

In short, since first appearing in the press at age 10, Liam's public presence has grown exponentially each year as he follows his passion of music. He and his brother are increasingly in the public eye. For this reason and our family's commitment to a better understanding of unschooling and disability, we believe our story should be told as is with names attached.

I do not detail much of the information presented above in the autoethnography itself. Primarily because the focus of the autoethnography is on the everyday experience of unschooling, in particular unschooling a student who experiences disability. Also, because I believe the experience is not typical of most unschoolers. I do not believe Liam's musical journey would have unfolded in such a way in public schools, in fact I believe quite the opposite that compulsory public schooling would have prevented his love of music from flourishing, therefore preventing his rise in the music industry, not to mention without unschooling he would not have had the time to pursue such interests. However, focusing unnecessarily on Liam's life story around music may reify the notion of super achievement (Dwyer & Peters, 2019) in homeschoolers. Super-achieving is a myth that many homeschooling families buy into, that because they do homeschool their children that those children should be super achieving students in some way. The same caution should be taken with Kenyon not to reify the notion of *supercrip* (McRuer, 2006; Shapiro, 1994) in which the "belief that a disability could be overcome…[by] the inspirational disabled person" (p. 16). Liam and Kenyon both are people first. Their individual journeys are just that - a journey, their journeys, and one of the struggles in

writing up this research will be walking the line between narrating achievement versus the everydayness of the unschooling experience without an emphasis on achievement.

Reliability and Validity

For a graduate class I conducted a critical textual analysis of characters in the television show *Glee* who experience disability as Down syndrome. I hoped to better understand representation of the disability experience in mass media and society, not just as a snapshot of this particular historical moment, but also to understand the portrayals as a queer re-imagining of disability experience that perhaps opens a new space for people experiencing Down syndrome to be in and with the world. In short, I was not attempting to discover the correct interpretation or most common interpretation of the text, but instead to articulate a political, queer reading of *Glee* as a text for re-imagining the disability experience. Media images shape the cultural construction of disability and Down syndrome, just as it does most cultures and identities. However, queer readings of media images can illuminate not only what typical meanings audiences make, but what new meanings can be made. *Glee* offered an opportunity to explore the critical notion of immanence; to go beyond describing how the world is, to envisioning how the world could or should be.

For me as a researcher, there is no a need to take a rationalist, objective, or neutral stance in my work, because I do not believe those aims are possible. I believe all methodologies are inherently limiting and partial, so universalism is never my aim. Instead I work to reveal how my knowledge has been produced, to acknowledge that power resides in what we claim as knowledge, that there is no such thing as objective

knowledge, and that all representation of knowledge is a form of power (Kincheloe, McLaren & Steinberg, 2011). Though I may make claims of highlighting expressions of power, or knowledge, or identity formation, I do not seek to claim truth or universalism. I only seek to open up new spaces of knowledge construction as sites for struggle as we make meaning of the experience of Down syndrome, disability, and ability in the world. In this autoethnography I do that through storying my family's experience unschooling.

For me as a researcher, there is no a need to take a rationalist, objective, or neutral stance in my work, because I do not believe those aims are possible. I believe all methodologies are inherently limiting and partial, so universalism is never my aim. Instead I work to reveal how my knowledge has been produced, to acknowledge that power resides in what we claim as knowledge, that there is no such thing as objective knowledge, and that all representation of knowledge is a form of power (Kincheloe, McLaren & Steinberg, 2011, p. 164). Though I may make claims of highlighting expressions of power, or knowledge, or identity formation, I do not seek to claim truth or universalism.

That said, my work is political. I am working toward transformation, toward social justice change, toward making life better for those at the margins. I echo Denzin and Lincoln's (2011) challenge to those working in the social sciences, "we want a social science committed up front to issues of social justice, equity, nonviolence, peace, and universal human rights" (p. 11). I am not attempting to claim a real or accurate representation, I don't believe that is possible for any researcher. If my articulations, interpretations, and academic creations serve as a liberating praxis for those at the

margins, or disrupt the actions of those who hold power in this unjust world, or move someone with the privilege of ability to reconsider their view of the world, or even just create a better world in some small way for my son — my research was/is valid, to me.

Contested knowledge becomes an apt phrase for summarizing my work. Contextualizing knowledge is what a scholar does with critical theory by articulating the various social, ideological, and historical locations of the researcher, researched, and research act. However, no matter how much contextualization is provided in the academic product, there will never be complete agreement on the validity or reliability of the knowledge produced, nor will that knowledge stand for all time. So through the lens of critical theory, all knowledge is contested, even contextualized knowledge produced by critical theorists. Every research act is a political act. However, when you pull back the curtain to reveal the process and reasoning behind your choices of what to highlight and what to silence — the research becomes closer to being valid and reliable, more so than any research that claims to be *objective* without revealing such inevitably embedded biases in the research process.

Contextualizing knowledge is what a scholar does with critical theory by articulating the various social, ideological, and historical locations of the researcher, researched, and research act. However, no matter how much contextualization is provided in the academic product, there will never be complete agreement on the validity or reliability of the knowledge produced, nor will that knowledge stand for all time.

I do want my writing to go beyond the last word on the page. I hope my research does not end with its writing. My work seeks not a monolithic end in a conclusion of

truth but hopes to create an embarkment for social justice action. The test of validity becomes a question of what action do people take after experiencing my work? Does my work serve as a launching pad for transformative action? Does it open space? Does it allow a space for previously silenced voices to rise?

As scholars, we must begin the shift toward new forms of knowledge production that imagine a new promise of social justice and we must build free and open bridges to give all people access to that knowledge. All scholars must become critical scholars who reject the neoliberal market, embrace social justice, respect global communities, and commit to the concerns of human dignity though radical love. Meyer & Lesiuk (2010) describe Freire's concept of radical love as action, "to increase our capacity to love, to bring the power of love to our everyday lives and social institutions and to rethink reason in a humane and interconnected manner" (p. 3). The future of knowledge work for all work in the academy no matter where it falls under the umbrella should be contextualized, skeptical of profit and capital, grounded on social equity and justice, dedicated to the alleviation of human suffering, working to unveil power, and promoting democratic living. My role? To present rich descriptions of process to show how the research is enacted. To dismantle the ivory tower one brick at a time in hopes of creating a more open and freer field in which the lines blur between researched, researcher, and reader. To keep delving into the rabbit hole, where research is never the same, but always transformative.

I am fortunate to reside in an open academic department that values: connections between the arts and the humanities, education and culture; integration of the

personal/professional self in perspective; crossing borders for interdisciplinary work; exploring the philosophical, moral, and spiritual; studying the post-modern; focusing on relationships between diverse fields; and encouraging emerging forms of inquiry ("Doctorate in philosophy in educational studies with a concentration in cultural studies," n.d., para. 3). Studying inside such a supportive environment scaffolds my work to enter into more open spaces toward expanding what counts as research. If scholars can't choose radical research in a cultural foundations department, then where?

I am not here to prove, but to describe. I am not here to nail down, but to open up. I am not here to explain, but to complicate. I am not here to explicate, but to imagine. I must seek to unveil the powers in the so-called neutral and objective traditional academy by creating new knowledge work through articulating the story of my personal praxis. I must story my journey as a scholar in a constant state of becoming. I must disrupt and fracture. Spry (2001) notes the role of the autoethnographic text in this process writing, "autoethnographic texts reveal the fractures, sutures, and seams of self-interacting with others in the context of researching lived experience" (p. 712).

I must connect. I must employ the storied life as a scholar. I must embrace the prophetic nature of this journey described by Dr. Martin Luther King Jr., "the arc of the moral universe is long but it bends toward justice" (Scott & Brockriede, 1969, p. 165). I follow that bending arc toward social justice. Each word I write is a step across the bridge from *what has always been* in the academy to the critical pedagogy notion of *what could be*. I am ready to travel through this new domain of what is possible when we open up to new expressions of what counts as knowledge work in the academy.

Positionality

Positioning oneself as researcher becomes a way to acknowledge how one's position, informed by multiple identities in flux and under constant reproduction through social construction, impacts how a researcher socially constructs the world (Kezar & Lester, 2010). Writing about positionally becomes a way to address not only our subjective views as researchers, but how our fractured, fluid identities intersect with power, all in the varied contexts we find ourselves in as researchers. Bourke (2014) writes:

> [We] must be ever mindful of our subjectivities. Such is positionality. We have to acknowledge who we are as individuals, and as members of groups, and as resting in and moving within social positions. (p. 3)

Chiseri-Strater and Sunstein (2012) warn researchers to become "conscious of ourselves as the key instruments of the research process" (p. 111). The authors challenge researchers to read self as any other text and then write that reading into the study. I offer an autoethnographic story as a way to address my own positionality.

Quilting

I loved exploring my grandmother's attic. The only way inside the triangular room running above the entire length of the old, brick house was a set of rickety, folding steps right in the dead center. I'd jump to reach the frayed pull-cord dangling from the ceiling, but it was always just out of my grasp. The strings on Grandma's handmade apron I could reach. I begged her take me to the attic, leaving the kitchen where she spent hours upon hours sewing at a small table in the corner. The pleading didn't work in the

afternoons when she listened to her "stories" on the CBS daytime soaps. She had to know who killed Victor this time, a reoccurring theme in the show. In the mornings, she tuned the radio to the local public radio station to hear the news on the hour, every hour between long stretches of Copland, Debussy, or Holst. I'd sit on the porch flipping through Grandpa's latest issue of *Progressive Farmer* and listen to the monotone disc jockeys describe the epic musical adventures of Billy the Kid in *Rodeo* or Brünnhilde's magical ride of the Valkyrie in the *Ring Cycle*. I'd close my eyes and the music came to life through my imagination. But when I heard the hum of the sewing machine click off, I knew I had my chance.

> **Memoir, around 1979:** Wagner's *Das Rheingold* blares from the radio. Grandma hums along. I sing, "kill the wabbit, kill the wabbit!" She laughs. Piccolos trill. She stacks her fat-quarter fabrics. The tenor voices of the violoncellos rise. She checks a pot of butter beans simmering on the stove. The horns blow. She conducts her way to the hallway saying, "Ok, muttonhead, let's go clean the attic." The orchestral climax fills the house. She folds down the steps. We are ascending into Wagner's Valhalla. I peep into the dark space above. Thin lines of daylight seep in through corner vents. I flip the light switch. A snowstorm of color; deep layers of calico, batik, and patchwork fabric cover everything, obscuring what's underneath. Bolts, boxes, and bundles of cloth spill into one another creating a cacophony of rich, thick color. We slide piles of linen, shift stacks of old quilting magazines, and we begin to uncover to discover. "Oh, look at this Grandma!" I shake a clear box full of empty wooden, plastic, and metal spools. Taking rest on a cedar trunk she says,"Take it downstairs honey and make something out of it." Cleaning the attic is a process of rearrangement more than actual cleaning. She picks through scraps telling me what she had made just by the leftover piece, how she had to improvise, how it seemed hopeless, and how in the end it all worked out — "Here's the corduroy from those pants I made you last year…looky, looky, it's the velour I lost, I can use this for Elaine's quilt…look honey, moleskin, you don't see this a lot, before you were born, yes, but now…Oh, chiffon from your mother's wedding dress, let me put that where I can find it again." In the dusty recesses, I pull away a brittle, yellowed linen. Something is buried here. I can see a black box partially hidden underneath pink insulation. I open the rusty latches on the half-moon case. My imagination runs

> wild: money, gold, or a gun? Slowly lifting the lid I see it — a violin. Gently unearthing it from from the burial ground of its fuzzy, green lining, I hold it in the dim light: scratches scar the dark wood, loose ebony pegs hang at the scrolled tip, and a hole in its curved body appears to be the work of a mouse. I hear Debussy's *La Mer* rising from the radio downstairs. I cup the instrument's bottom between my chin and chest. I stroke my small hand up its dark neck fingering the strings as I go. I eye the thick top string and pluck. For a moment, I disappear sinking into fantasia, lucid and dreaming, voices rise, a timpani rolls, the plush red curtain rises, and…Grandma coughs. She has that cocked eye on me she uses to get me in line. In a very matter-of-fact tone, she says, "Sweetie, let's put that back exactly where you found it." I obey. "And don't mention you found it to anyone, ok?" As I finish covering it back up, she is halfway down the steps yelling back to me, "Time to go down and see who shot Victor this week."

Like Wagner's mythic Valhalla, where both the gods and the dead ascend to escape the empirical world below, the attic became a mystical retreat from the world of *what is* into a magical place to dream of *what could be*. Much like the Norse legends Wagner based his epic *Ring Cycle* operas upon, my version of Valhalla in Grandma's attic became not only a resting place for the dead, but a site of rebirth. My grandmother kept everything: scraps, strips, buttons, zippers, empty spools, out-of-fashion, out-grown, or just unused — it all found its way into the attic. Each piece represented a story, a connection, a remnant of the past: a swath of faded blue with white polka-dots reminded her of the dress she made for a trip deep into the mountains to buy moonshine when she was a teen; tattered, tiny moth-eaten squares that her mother cut for a quilt took her back to growing up in the Great Depression; and a smooth, yellow silk used for a prom dress brings about a lecture on how my parents married too young. She could mine this scrap heap for whatever task was at hand down below at the sewing table. Each project started with a pragmatic question: how to keep warm this winter, what to give for a wedding gift,

or what to make for a new grandbaby? From the question eventually came a product: a scarf, a quilt, or a baby blanket. Always working toward a final product, my grandmother had to first find a place to begin: a fussy-cut inspires a pillow-top project; a hue she saw in the sunset infuses her embroidery work; the tone of a baby's angel kiss serves as a base color for crochet; the texture of a country-ham slice triggers the use of rough leather for a vest; or the sound of split pine-kindling crackling in the fire conjures an image of mixing rhododendron and log-cabin patterns in a quilt. She observed the world in keen detail using what she found to make new things or things anew. The starting point sparks a connection — into the attic she goes to harvest from the materials at hand to begin the complex and rigorous process of creation. If she couldn't find enough material in the attic, then she headed to the neighbor's house, or my aunt's house, or any of the women in her quilting circles who all maintained similar stores of fabrics, patterns, and threads. Even if she didn't find the material she sought, the dialogue, the exploration, the work in the field made connections, unveiled options she hadn't considered, and changed the direction of her project.

Always in tow, riding shotgun, unbuckled in her boat-like, white Chevy Impala, I'd accompany her into town to the Cone Mill employee store or to the Sears outlet. She improvised inside these stores in quantitative fashion calculating length, analyzing costs, and comparing textures. She also used qualitative ways by substituting patterns as the need arose, initiating side-by-side comparisons, impromptu interrogation of bystanders or store clerks for opinions, observing what others were buying, taking fabrics into different lights, and interviewing other women about their own project's past, present, and future.

She relied on experience, instinct, and a tool bag of theories and methods to know what to do in this field. She returned as often as needed to get all the material, but she worked with the tools at hand always critically considering what she was doing, how, and why. She pulled out techniques from the tool bag at the appropriate time. If she didn't have the right tool, she improvised by layering patterns on one another or splicing them together. She didn't stick to one monolithic way of sewing, she pulled one idea from McCall's and another from Simplicity, and yet another from Advance. She did this all in the field, as well as when she returned home to that small table in the corner to sew. She used an array of scissors, needles, threads, fabrics, rippers, stencils, erasers, pins, cutters, clamps, wheels, rulers, but her main tool was her vintage black and gold Singer sewing machine. She threaded, she wove, she laughed as she worked, she talked to herself or the machine, she cursed, she sewed for hours on end without break. Today, I can close my eyes and see her: leaning into the machine adjusting the feed dogs; stacks of fabric flanking her; scraps scattered across the floor; yellowed, crinkly patterns tacked to the wall like treasure maps; jelly jars of buttons at her feet; and she with her wavy, silvering hair, her ever-rounding body, and freckly-white Irish skin, becoming lost in the moment of creation. In that memory of the past, I see myself, too. With each passing year, I look more and more like I remember her. I hear her words echoed in my own.

Though I'm now comfortable with becoming more like my grandmother, for much of my life I worked to distance myself from the culture of my youth. For years I only could see narrow scripts of rural poverty played out in white-trash, redneck, and uneducated lives — a destiny I had somehow escaped. I became a first-generation college

student and intended to never look back. I hid my Southern drawl. I invested in learning and building the cultural capital I thought I needed to succeed in what I saw as a rich, white-man's world — a world I had only seen from the outside. I learned the etiquette needed not only to be invited to sit at the man's table, but to know which fork to push into the pork. I learned to network through golf and good old boys, two systems still well-entrenched in the South. I dressed the part and acted the part of middle class. I discovered the system and worked it, becoming a cog in the machine. I climbed education and employment ladders always suppressing the desire to return to something I refused to call home. I had learned and built the social, political, economic, and cultural capital to survive and thrive in a middle-class, working, suburban existence that was fed to me as achieving the American dream. I had escaped trailers, red dirt, Kool cigarettes, and fatback. I had found culture, right? I had money. I had a title. I had an office. I had a big house. I had seen *Das Rheingold*, but did I hear it? Had I forgone love in a quest for power like Alberich? Was I the naive Siegfried who knew no fear? Was my self-created Valhalla destined to crumble back into the waters of the Rhine?

All my kin folk resided within a 40-mile radius of each other. As they dropped out of high-school, got pregnant, had babies, worked in the mill, and had their children repeat the process, I wondered how I escaped? Merit? Hard work? Luck? Or was it really an escape? Perhaps, I was the one who was lost all along? As a young journalist I saw the world through a positivist lens as I sought the one version of universal truth that was out there to be discovered and reported and written by me. I toured rich, white suburban schools and poor, black inner city schools during my stint as an education reporter and

wrote story after story based in a myth of meritocracy. Did my work change anything? Did I reify the very power structures that sustained the problems that gave me stories for which I got paid to write? After leaving journalism for public relations, I began to develop a post-positivist eye for the relativity of truth. I participated in and witnessed how power shapes perceptions of pre-packaged notions of truth presented to the public for consumption. Truth became the realm of those who could afford to produce it, or hire people like me to produce it for them. I wrote speeches for talking heads to give to publics that made me feel like a puppeteer in Plato's cave. I didn't lie, not really. But I didn't reveal the entire truth around sensitive issues that would hurt the image of the organizations that paid me. Our office manipulated data, budgets, words, and images to serve our own empire building. Burned out and disgusted, I left the 9-to-5 world of suits and ties after the birth of my first child to become a stay-at-home parent. About that same time, I started to teach undergraduates at my local university. In this, I discovered a passion for the process of teaching and learning. I returned to graduate school for a master's degree in liberal studies and began a Ph.D. program in cultural studies with a heavy dose of communication studies as well. My coursework exposed me to critical theories, critical pedagogy, and postmodern perspectives that kept returning me to questions of how knowledge is constructed, what counts as knowledge, and the interpretive nature of being in the world. Drawn to qualitative inquiry across the multiple disciplines of educational studies, cultural studies, communication studies, and liberal studies, I describe myself, at this moment, as a deeply interdisciplinary scholar specializing in radical research and pedagogy toward social justice transformation. My

epistemological perspective privileges the construction of new knowledges that disrupt the status quo, a status quo that includes the very academy that shapes me as a scholar. My ontological perspective privileges the hermeneutic nature of a critical constructivism that seeks to unveil power through a focus on the production of self. My methodology is autoethnography. My academic products are critical, literary, interpretive, performative autoethnographic works. I'm a storyteller, just like my grandmother.

I am beginning to see the connections between my grandmother's life as a seamstress and mine as a scholar that make us more alike than I ever imagined. If I describe myself as an autoethnographer, then I must describe her as one, too. She worked in cloth, I work in words. Her quilts were rich in color and texture, and thick with layers of cloth and batting. I too, seek to produce thick and rich texts that are as rigorous and complex as her quilted creations. The scrap heap in my metaphorical attic is chock full of journals, memoirs, artifacts, photographs, videos, recordings, paintings, poetry, short stories, notes scribbled on napkins, and an endless collection of dead junk that has potential for rebirth into new knowledges. When I begin my work as a researcher, I, like my grandmother, start with a pragmatic purpose: to fulfill a course requirement, complete a dissertation, or publish in a journal. My starting point is a question or questions inspired perhaps by a memory, image, event, experience, law, policy, trend, or some text. Predicting the final product becomes impossible because my research, like my grandmother's quilting, does not proceed in a linear manner. I research, write, return to the field, write, research, write, and return over and over. Though I will have a final academic product, the process of creating it becomes more important than the actual final

product itself. I dig in my personal attic. I enter the field. I wield an ever-growing tool bag of theory and method that I deploy at the appropriate time in the unfolding context of the research act. I enter fields and walk the borders, writing in the margins as I go. I return and write and return to the field again. My knowledge work becomes a montage of theory and method in the process. I don't have a Singer sewing machine, but I spend my time leaning into a 27-inch black and aluminum iMac surrounded by stacks of printed PDFs, books fringed with multi-colored page tags, and walls papered in Post-it notes. I work intently, only seeing one small section at time. So, like my grandmother spreading the quilt pieces out on a bed to see how it all fits together, I draw out concepts on white boards, and print pages to spread out on tables, all so that I can move from micro to macro and back again, and to get the pieces to fit together. Instead of blocks of fabric, I weave together stories to create a quilt-like final product. As each quilt has a story of creation, so does my research and that story is embedded in the final product. Writing becomes a way of knowing, a way of interpreting, a way of being, a mode of analysis, and a final product. In each quilt, you not only see the final fabrics, patterns, colors, and stitches, but also detours, mistakes, and signposts of the process of creation such as tie knots or basting stitches. So too, in my autoethnographic method, I write the messy process.

The quilts my grandmother made live on even though she died in 1996. Some decorate walls, some cushion crawling babies, and others warm lovers on a cold night. A quilt is an interpretive project. It has different uses for different people. How you turn it matters. Four orientations give it four completely different meanings. Flip it upside down

and the backside can be read as a text. Some people only see the flat surface, while others see the montage of layers as patterns overlap and blur into one another. One person sees liberation in the positioning of a defiant Sunbonnet Sue pattern looking out from the quilt borders. Another sees an aesthetic simplicity, while another sees chaos. There is no correct reading of a quilt. So too, my writing becomes a mosaic that must be interpreted by each reader. I do not have one truth for the reader. I do want the performance of my writing to go beyond the last word on the page. I hope my research does not end with its writing. My work seeks not a monolithic end in a conclusion of truth but hopes to create an embarkment for social justice action. The test of validity becomes a question of what action do people take after experiencing my work? Does my work serve as a launching pad for transformative action? Does it open space? Does it allow silenced voices to rise? Like the leftover scraps from my grandmother's projects, the scraps of my writing await a rediscovery and repurposing as I enter into the research process again. I weave together a narrative, not as an answer to my original question, but in response to it, an echo, an exploration — what people make of it, how they interpret it, is out of my control once I'm finished making the final academic product. Just as it's impossible to truly know the impact of teaching, at least beyond the reductionist measures of quantitative testing, it is impossible to know the true impact of research. Like the quilt made by a stranger given to my partner and me to cover the isolette during our newborn's month in the NICU, I hope my research provides connection and comfort in an increasingly sterile world. Like the quilt my spouse made both as a conversation starter about diversity and to commemorate the life and death of a student who experienced Down syndrome, I hope my research

heals. Like the last quilt my grandmother made that was given to me as a wedding present, I hope my research always looks to the past with hope for the future.

My grandmother is part of me. One fourth of my chromosomes are hers. I do not sew cloth; I never developed the skill or eye, but I do sew words. My fabrics are stories. My threads are theories. My methods are patterns. My quilt is my story. I research and write with love, just as my Grandma quilted with love. What follows is my quilt. It's thick and rich. It's not divided into predictable and expected academic boxes. It's a tapestry, montage, collage. It's fluid, complex, interpretive, and at times, chaotic. Turn it. Look into its layers for meaning. Allow the patterns to blur into one another. Hold it close. Step back. Interpret. Cuddle up and stay warm. I present it with radical love and hope for social justice transformation.

Glimpses

Throughout this work, I will use a performance technique called *glimpses* named by Marcelo and Moreira (2009) and used in their book about decolonizing knowledge *Betweener Talk*. Glimpses are short narrative looks into the past with no particular form or format other than an indication of the timeframe. In certain cases, I have added the context of the communication format such as email, journal entry, etc. The glimpses serve as contextualizing narrative elements.

CHAPTER IV

AUTOETHNOGRAPHY

A Deschooling Story

GLIMPSE, around 1981: I was uncomfortable. But wasn't everyone? It was school after all. I shifted my leg underneath my bottom to provide some cushion against the wooden seat. All the boys sat on one side of the auditorium laughing at fart noises or stupid jokes, while the girls shot disapproving looks from across the aisle. As sixth-graders and the oldest kids in school, we were too cool for school-wide assemblies, especially ones involving music and dance.

Principal Jones glared at us through his thick, black-plastic, military-issue bifocals and yelled at us to "pipe down." What a prick. He had been my mother's principal, too. In my three years at this public school, I had only been in his office once; to witness my best-friend receive 10 licks from a thick, white-oak paddle for having "distracted" the bus driver. Since it was my first offense, I just had to watch. I thought he was perverted. A grown man making an 11-year-old boy watch as he bends another young boy over a desk and spanks him.

Mr. Jones motioned for the last group to come out onto the stage. A group of 12 or so students slowly lumbered their way onto stage, somewhat reluctantly, some led by hand by teachers, some in plain clothes, but some in crude, cardboard costumes that looked like giant moonshine jugs and others in tattered dog costumes.

Someone back stage dropped the needle onto the record player and with a scratch and a hiss music began — and the kids danced, sort of. They sang too, sort of. There were several teachers, ones I had never seen before. They moved in and out of the kids pushing and prodding and smiling at them and encouraging them to sing *Little Brown Jug.*

I had never seen any of these kids in school — ever. *Ha, ha, ha, hee, hee, hee.* They had thick glasses and ill-fitting clothes. *Little brown jug how I love thee.* Lenny Wilkes leaned over and whispered, "look, it's the retards." *Fiddle dum, fiddle dee.* I didn't understand. *Little brown jug, oh, you're for me!*

> How could there be a dozen kids at our school that I'd never seen before? Where did they eat? Why weren't they on the playground? Why didn't I see them in the bus lot? It was a small school. Where was their classroom?
>
> The music stopped — a smattering of applause. We went back to class.
>
> **GLIMPSE, July 2004:** The doctor said he wanted to transfer our newborn to the NICU in Hickory. He paused. Then he said the nurse suspected a problem and with our permission they could do the blood test to confirm Trisomy 21. What? Down syndrome, he explained. His cell phone rang. He left. We sat in silence.

The Two Most Useful Words in Social Justice Work: Fuck You

> Pissed-off research…when I think about ways in which people are segregated, persecuted, and denied basic human rights, I get pissed off. My research and analysis reflect that; my words, thinking, and results reflect that. Passion, I think is a good thing — it can drive us to explore ideas and thinking and understandings in ways that others take for granted. (Smith, 2006, p. 3; Ware cited in Smith, 2006)

I can try to story times in my life I felt marginalized. Most of those stories were in my childhood. But as an adult I have found myself seemingly always moving purposefully toward the margins. I became vegetarian in a world that privileges meat. I became atheist in the Bible Belt. After becoming pregnant, we exited the status quo of the hospital system to avoid being another commodified birth experience dictated by a patriarchal medical system. We drove nearly an hour to see a midwife and to have our baby outside of our county, which was not midwife nor natural birth friendly. We became certified natural birth educators to combat what we saw as a birth machine turning a once organic, natural experience into a mechanized, profit-centered enterprise that packaged and sold a drug-induced birth process that ushered both parents and babies into the

schooled world of obedience to the status quo. We became breast-feeding support volunteers through our natural birth classes, free workshops, and La Leché League training so that we could break the cycle of the commodification of feeding by formula from companies who seek to put their products between what should only be mother and child. We formed an anti-vaccination support group to aid parents who sought to avoid or reduce the dozens of so-called *mandatory* injections of corporate-funded vaccines in every child. So we fought back against the machine in an effort of radical love to free as many people as possible. That work put us on the margins in our community as those radical birth educators, those radical breast-feeding people, and those radical anti-vaccination people ruining the herd's immunity.

Perhaps nothing put us on the margins more with my family, many friends, and co-workers as when I quit my job as a Director of Public Relations and Marketing to become a stay-at-home parent. They said, "you're throwing your college education away," "that's not what men do," "that is what daycare is for," and "normal families don't do that." But we did. Janet was the breadwinner and I tied on an apron, cooked and cleaned, and changed diapers. At the playground the mothers called men who stayed-at-home *wolves*. They didn't like us because we didn't socialize with them or with each other for that matter. They said we just stood at the corners of the playgrounds with our kids avoiding social contact. It was true. "Why don't y'all form a group 'daddy's morning out' or something?" they asked. But the few stay-at-home dads in our community didn't really care to hang out with each other. We really were wolves — lone wolves.

But nothing in my life indoctrinated me into the experience of marginalization as much as the birth of my second child Kenyon. It is a story that is continually unfolding. But I believe the autoethnographic telling of our family's experiences of marginalization is a worthy academic endeavor to bring light into that liminal space where so many parents of children who experience disability become schooled by society being told how to raise their children, how to be a cog in the machine, how to be known, where you can go, what you can do, where you can park, how you should feel, and who you and your children should be.

The scripts are rigid and handed down as unquestionable paths to follow. From the moment of a diagnosis of congenital developmental disability, your child and your family is marked and monitored by Foucault's Panopticon (Danforth, 2000) embodied through the agents of nurses, doctors, geneticists, and social workers who tag your child as *disabled* and reports them through the Child Find ("Project Child Find — Exceptional Children," n.d.) posse of child development services agents who find you, catalog you, track you, and show up at your front door before the cheap, foil *Welcome Baby* balloons have time to lose helium and fall to the floor.

"Hello and here is your IFSP, can we schedule your first OT, PT, ST, and TT sessions this week?"

TT?

"Oh, that's technology therapy, it's a new service we can bill for, oops, I mean provide."

And so your family's schooling begins. They come and measure and quantify your newborn and write cold, hard, factual proclamations on colder, harder, institutional, black and white forms.

"Sign here, here, and here."

They calculate your child's mental age as a negative and tell you. "So, he was 8-weeks early, plus developmental delay, so right now that puts him at a negative…" What the fuck? That woke me up from my slumber. A month with a newborn in the NICU, a five-hour brain surgery, a diagnosis of Down syndrome…we all were in a fog and just rolling with life, trying to make it through, trusting in the system, but what the fuck? Here is this agent telling me my child is a negative 21 weeks old? All so clinical, too. "Show and repeat, show and repeat — that is is your new mantra, he'll never learn independently." Fuck you. Yes, fuck you. I wasn't just pissed off, I was mad as hell.

Our journey out of being complicit in our own oppression had begun. If this is what people with kids who experienced disability did, then we were moving out of the center and finding the margins. The margins were always safe spaces where we could be free to discover new ways of being in the world. And the vision of Kenyon's future presented to us was not a vision I was willing to accept. And our journey began with two of the most useful words I've found in social justice work — fuck you.

> **GLIMPSE, email, 2005:** Neurosurgeons don't have much of a sense of humor. A good thing I guess. I asked ours how much brain tissue our son Kenyon would lose due to the surgery he was suggesting. He said think of it like a straight needle-size hole. The area of the brain that controls your thumb is about the size of a nickel, so imagine a straight needle going through nickel. I asked if he could

try to hit the part of the brain that is responsible for the rebellious teen. He didn't laugh.

He was pretty blunt. If the surgery is required, there would be a one in three chance Kenyon would die in surgery. Are those really the best odds we can get? Our chances of having a child with Down syndrome were one in 675, and our chances of having a child with hydrocephalus was one in 1,000, and the odds of having a child with both unrelated conditions plus being two months early (also unrelated to Down syndrome and hydrocephalus) were astronomical, so we're dealing with one baby that is pretty adept at hitting the odds. I think we should plan a trip to Vegas and let Kenyon pick the numbers.

There is also a chance of damaging brain matter during the surgery, he said. But overall, for Kenyon's age, his chances were 30 percent of being a totally successful surgery with no complications. Sometimes I think he's just making numbers up as he goes. The percentages really don't matter because it is a situation where, if we did nothing, the doctors say the ventricle would continue to enlarge until it killed Kenyon.

I sometimes wonder why we put so much faith in what the medical community says. Our faith in the medical system has been challenged over and over throughout Kenyon's short life. While there have been shining moments of greatness and extremely talented people and kind workers, we have also seen mistakes, wrong medications, a nurse in the hospital who took our older son Liam's vital signs while he was sleeping instead of Kenyon's, and conflicting opinions between the neurosurgeon in Charlotte and the one in Winston and then what I call the best mistake of all.

At our December meeting with the neurosurgeon, he showed us areas of Kenyon's brain described as "permanent" brain damage. His exact words while pointing to the dark areas on the outer edges of Kenyon's brain were "These areas will NEVER grow back." In February, Kenyon had his first fever and began spitting up. Two major signs of his shunt malfunctioning. It was Superbowl Sunday. At kickoff, we were in the hospital. Kenyon had blood tests, a chest X-ray, a CATscan, and every other test you could imagine. Turned out to be a stomach virus, but they had to rule out the shunt malfunction because that would mean immediate surgery.

However, in the radiologist's office while looking at the films of Kenyon's CATscans, he said, "Look at this, his brain has grown back around the edges here where it was damaged." On Monday, our neurosurgeon confirmed that Kenyon's brain had grown back in that area of "permanent" brain damage and seemed baffled by it. (Purcell, 2008, p. 118).

Letting Go

All parents have a tough time on the first day of school. As a stay-at-home parent who spent every day with his child, save the 12-weeks maternity leave immediately after birth, I had a particularly hard time letting go. At least I had Kenyon. Kenyon is Liam's younger brother by two years. After dropping Liam off that first day, Kenyon and I drove out to lunch, did some shopping, anything to keep our minds off missing Liam. Being with my child, caring for my child, reading to my child, playing with my child, learning alongside my child — all these experiences seemed so natural to me as a stay-at-home parent and I couldn't imagine a life of leaving my child at a daycare with strangers each morning only to return eight or nine hours later to pick him up, and now I was having a hard time imaging his life going on without me, and without Kenyon. But this was the right thing to do, right? This is what public schools were for, right?

We picked a house in a good school district. He would be fine. He would be at the head of his class, I'm sure. He will be safe. I was always thankful for the cultural, social, and economic capital that our privileged lives allowed us to choose to have one parent stay at home with the children. I grew up with a single mother, as a latch-key kid, and for a time, in a life of poverty. I worked to make sure my own children didn't have to endure what I endured growing up. I should have been happy. Liam had a home to come home to where a parent would be there. But still I couldn't help feel alienated from that which I felt naturally belonged together. Life was out of harmony. But, I just had to learn to let go, right?

GLIMPSE, around 2006: I'm volunteering at my son's elementary school. I'm helping shovel mulch onto the pre-K playground. The teachers are installing a half-foot high plastic barrier all the way round to keep the mulch around the equipment. I ask, "why don't we leave off two sections of the barrier so a wheelchair can get onto the playground?" The lead teacher responds, "but we don't have kids in wheelchairs here."

Spotting a Red-eyed Vireo

I hold Kenyon up
turning his good ear toward the weeping
cherry tree chockfull of cotton candy blossoms

whoring themselves to seemingly thousands
of bumble bees moving in and out
in and out.

Slow syncopated buzzes blend
together, a symphony of drunken snare drummers
resting with each dip into the nectar, rolling again after each drink.

My bad shoulder pops as I lift
his limp little frame higher to hear
the Red-eyed Vireo calling *myahh, myahh*.

Slurring up in broken notes
the little olive-gray demon sings
as if asking a question.

I can see the bird, but not hear it anymore,
not over the creaky chorus of park swings,
a half-dozen rusty metronomes set random.

Not over the intermittent steely clangs
of horseshoes and ensuing banter
about leaners, stint surgery and who's moving to Florida.

Not over two nearby young mothers
squawking their bedroom gossip
back and forth

over the incessant begging
voices of snot-sniffling two-year-olds
demanding juice and Cheerios.

A crescendo from the east soon drowns
out all sound in Freedom Park save
the low-flying 727's twin jet-engines.

As the deafening wave of sonic blur ends,
so returns the mad-house cacophony
of a public park afternoon:

the basketballs ting, ting, tinging;
dirty little children scream, scream, screaming;
a low-riding '64 Chevy rolling, bass thump, thump, thumping.

The bird now gone, we sit down to watch
an out-of-place young couple — high school,
maybe college-age — swing on the monkey bars.

I dream of Kenyon growing
up, one day like this cut young man
playing, smiling, flirting

whispering hopes and dreams into some girl's
sandy locks of hair as she sways upside down
tucking in her shirt with one hand.

The young man leaves her, walking away
Neanderthal-like, doing a really bad
Groucho Marx impression.

Still upside down she whistles
a cat call and catches her shirt
before it falls too far.

Hunched over he drags his hands scooping up mulch
hurling it back toward her
then crashing into a trash can he feigns a fall.

She flips off the bars and follows
beaming, smiling, she yells to him
quite affectionately, *you retard*.

In a deep, throaty slurred moan
he calls back to her mockingly,
a drunk laughing Frankenstein, a fool.

She skips toward him laughing. She is close
enough that I could speak
She yells *wait up, you fucking retard*.

I clear my voice, she glances.
I smile and wave her over.
She comes.

I hold Kenyon up.
Bending over she coos
cute baby, he's beautiful.

Nose to nose now, a silver cross on her necklace
and a charm of Saint Bartholomew
tinkle together.

I start calmly, *he is beautiful*, I think
deep-blue almond-shaped eyes,
a flat nose, but distinctive.

She's smiling.
He's retarded, I say and smile.
A fucking retard, I suppose.

Smiles gone. I continue,
after he was born
an old uncle of mine told me he befriended a retard once

and that all he could remember
was that he looked like an orangutan.
What a terrible thing to say, huh?

Clutching her cross, feet shuffling
backing, cheeks flushed, she's going to cry,
but manages a raspy *I'm sorry.*

I brag, *I've heard much worse*
than her offense to me, almost daily on TV,
on the radio, walking downtown, in the park.

I say, *shhhh, look at that bird.*
It landed and pecked the ground.
It's Red-eyed Vireo, birdwatching's a hobby.

She's so uncomfortable.
Maybe guilt keeps her here.
I keep talking as she continues to back away.

You'll never see it at the feeder
fighting for cracked yellow corn
or on the cover of Audubon.

But it sings its joyful lament from dawn to dusk
living a life of contentment
sharing its song for those who will hear it.

I hold Kenyon up
and whistle *myahh, myahh*.
She smiles, sort of, in a disturbed way.

Mouthing *I'm sorry* she turns and runs to her boy
who by now is busy revving his engine for fun.
I put Kenyon on the ground,

his fat little hands holding my fingers, he pulls
forward with all his weight, swinging side to side
like a damn orangutan.

He drools in the sand.
We sit and watch the little toddlers crawl,
walk, hit each other with sticks.

And all I want is for Kenyon to share in my joy
and the Red-eyed Vireo in the cherry tree
calling out *myahh, myahh*.

Asking its eternal question
from dawn to dusk each Spring in Freedom Park.
I hold Kenyon up.

GLIMPSE, around 2008: We're driving home. Liam says, "we shouldn't vote for Obama." I nearly drive off the road. "Why?," I ask. "Teacher says he's not a

veteran, and that we're not inviting him to our Veteran's Day celebration. We're all writing a letter to McCain to invite him. He's a veteran."

GLIMPSE, Veteran's Day, 2008: The pre-K children line the sidewalks waving little American flags that were made in China. The second-graders line the halls chanting and cheering as the veterans walk into the school. The third-graders salute. A select few fourth-graders, the good kids, serve snacks and drinks. The whole school is decked out in red, white, and blue.

Each first-grader got to invite a veteran. Liam asked to invite his grandfather who was a peace activist. The teacher said, "no, we don't want any conflict at this event." I told her we were pacifists. She asked, "what's a pacifist?"

Parents weren't invited to the Veteran's Day celebration. But I came anyway. As Liam moved through grade levels this was a theme becoming more and more apparent — that parents weren't welcome. Not all parents, just some.

I was used to being excluded as teachers sent home notes addressed to Janet or asking for classroom "mothers" to volunteer or in general not being included when other stay-at-home moms were asked to volunteer. As a stay-at-home dad, I often had to force myself into inclusion in school.

When I got to the library I saw the typical suspects who were invited: the moms whose families donated money to the school; the moms who led the PTSA; the moms who were church buddies with the teachers; and the moms who were also teachers in the school. There were those who were in the know and included, and those who never knew and were excluded.

Seated in the school library the veterans smile and clap as the first-graders march in high-stepping it to *Johnny Comes Marching Home*. The highly choreographed routine ends with a salute. A PowerPoint slideshow of crayon tanks, guns, fighter planes, bombs, and flags runs in the background as each child comes forward and reads a thank you. The kids have autograph books. Someone asks everyone to bow their heads for a prayer. I see Liam bow his head. We don't go to church. We aren't Christian. Yet, he obeys. "In Jesus Christ's name, amen."

The whole event was a hyper-real, patriotic orgy of glory for war and blind obedience into one patriarchal, neoconservative notion of what it means to be an American. If the colors were different, if the music was different, this could have been North Korea or Hitler's Germany.

Natural Science

Remembering last year's Veteran's Day Celebration at school, I pre-empted having to deal with it by pulling both boys out of school and taking them to a science museum in a nearby city. After a long day touring through the museum, which both boys enjoyed tremendously, we came upon a group of kids who experienced disability. They were high schoolers and they were cleaning the entry area. The entry of the science center is a large circular glass wall that looks down upon a giant pendulum marking the time of day. There were a wide range of students who experienced developmental disability including several students who experienced Down syndrome. Spray bottles in hand, they wiped clean all the finger marks that other kids have left. We watched them moving about the museum cleaning walls, cleaning handrails, cleaning windows, cleaning the residue that other children had left behind as they explored the museum.

I asked one of the teachers what was going on? She said this was a *life skills* class from the high school. "Really?" She seemed shocked that I would find something wrong with the activity. She said they needed to be trained for a life working in preparing food or cleaning. Food or filth? Was this Kenyon's future? I asked if they got to tour the museum? She said, "No, why would they be interested in that?"

Inclusion is *Just* Education

> Inclusion is not defined — or even referenced — in the Individuals with Disabilities Educational Improvement Act (IDEIA)…this is in part a reflection of the way that education for students with disabilities has been described and understood for the past more than thirty years…education is framed as a place — an environment, one that is portrayed as more or less restrictive…[it's] a trap…the portrayal of special education (and, for that matter, eduction more

> broadly) as a place, rather than seeing it as process or set of practices…special education is where things occur, not what is done there. (Smith, 2006; Kluth, Villa, & Thousand, 2002, cited in Smith, p. 39)

I ordered a half dozen of each bumper sticker: *Inclusion is Just Education; Inclusion is a Birthright not a Privilege;* and *Think Inclusively, School, Work, Play, Community, Life.* I thought long and hard about which sticker to put on which vehicle. Janet drove our 1997 Honda Civic every day to the elementary school where she worked as a special education teacher. She parked in the teacher-of-the-year (TOY) parking space, a space she reluctantly accepted only because it would make getting Kenyon in and out of the car easier, since there was no accessible space in the lower parking lot. She didn't like the fanfare. She was a three-time TOY. She said it didn't mean as much this time, not after 15 years teaching and 10 years of No Child Left Behind. Ironically, each year the school would move the TOY parking sign to any space in any parking lot, but they couldn't put up one more accessible space in a lot that needed it. I picked the *Inclusion is Just Education* sticker for the Honda since it was the car that would be seen the most. It might have the most impact.

Would people get it? Would they read it — inclusion is easy to do? Or would they read it — inclusion is social justice? Or would it just blend in with all the other bumper stickers? I thought people would see it. After all they always commented when Janet wore a t-shirt to school on casual Fridays sporting a message (same struggle, different difference; any number minus one is still discrimination; inclusion, anyone, anytime, anywhere; and our school welcomes everybody). And even if the comment wasn't

positive, at least people were noticing, and maybe even thinking about changing how the school operated.

It might seem naive to think a bumper sticker or t-shirt might change a system. But it was something we could do. It was putting the idea out there. We firmly believed that by putting our vision of inclusive eduction out there into the world, advocating for it, trailblazing a path, and living it — that we could change the world into a more just place, and in particular, change public schooling by changing one public school into a place that practiced inclusion.

If we couldn't do it, who could? Our whole lives seemed to be building toward this moment when Kenyon entered school. Kenyon wouldn't be whisked off to the one central school in our system where all students with developmental disabilities were shipped to live lives of isolation in a so-called *Center of Excellence*, only coming out *en masse* to sell baked goods to the *normal* students as a fundraiser. Not our kid. We would be the start of inclusive practices at this school. We would change things. After all, Janet was a special eduction teacher with 15 years of experience, a two-time National Board Certified teacher, she held a Master's degree in special education — she was a damn good teacher who despite rejecting the high-stakes testing mandates of NCLB as a means of true evaluation, still managed to consistently lead students to higher scores than their so-called *typically-developing* peers. She knew the system and could guide our family through it. In addition to nearly 20 years of listening to Janet's stories and struggles and triumphs in public education, I had my own set of experiences as an education journalist, a public relations practitioner in education, a decade teaching in higher education, years

of volunteer experience in schools, and a background in educational studies as a Ph.D. candidate. In addition, I served on local, regional, and state-wide committees, boards, and panels involving public schools, disability, and education. It seemed our entire lives had prepared us for this moment. I proudly put several bumper stickers on each car.

We believed what the sticker said — *Inclusion is Just Education*. Inclusion is both easier than people think and the right thing to do. I kept the extra bumper stickers handy. Maybe one of Kenyon's teachers might reach out to us and ask for one. Maybe the principal. Who knows? It was an exciting time and we were full of hope.

> **GLIMPSE, August 2010:** Our second child, Kenyon, starts kindergarten. Kenyon experiences disability as Down syndrome. We've avoided special education services for the past four years since leaving the CDSA (Children's Developmental Service Agency) and asking them to shove our IFSP (individual family service plan) up their ass. The good thing about early intervention is that we learned we weren't going seek or be forced into special education services under IDEA. We were smart, experienced, and savvy educators who had a plan to trail blaze a new path of including children who experience disability into the classroom. Two years of pre-k went really well. The experiment was working. But principals changed. Teachers changed. Kindergarten was a whole new game.

Agenda Setting

August 2010 - This is the agenda I sent to Janet for our first meeting with Kenyon's kindergarten teachers to keep us focused:

- tell about Kenyon…
- he's intelligent — knows his letters, clever, use of technology
- he's a great communicator — uses signs, touch
- he's a people person — loves to be in groups, pairs

- he loves music
- Kenyon is perfect, and does not need to be fixed
- medical model of disability vs. social model
- our philosophical focus
- disability is natural, difference is natural
- disability is beautiful, difference is beautiful
- disability is welcomed, difference is welcomed
- we are all more alike than different
- celebrate our differences
- How to handle typical questions from students/parents — What's wrong with him? Why doesn't he talk?
- We're asking you to become advocates for Kenyon
- advocates for Kenyon and his success
- advocates for inclusion
- advocates for a socially-just society
- Big picture — Kenyon is going to graduate, we are building a community of support around him to make that happen, and we are hoping you all will want to be a part of that
- It is never IF, it is always HOW
- Equity vs. equality — not everyone needs the same thing, but everyone needs something in differing amounts

- Being creative — thinking how to differentiate
- Being flexible — letting him vocalize, stand, letting him be who he is and celebrating it
- Listening — taking time to really listen and understand his communication
- Loving — expressing love and allowing him to express love
- Focusing always on what is going right
- That he should always be included
- We are resources to be used!

Thank you

> **GLIMPSE, August 29, 2010, email from William to Janet:** Public schools are supposed to welcome and care for all children. A child doesn't have to have a label to be supported and cared for, right?

> **GLIMPSE, September 2010, personal journal entry:** This is so hard. Keeping up the facade. These emails and meetings take the life right out of me. You have to platform everything. You know they don't believe it. You know they hate reading it. I really believed if we could articulate a different way, a better way, that people would join in and support our vision. Why can't they see the world differently? Why can't they see another way? Why?

Platforming

We used platforming as strategy for communicating with teachers and administrators. Platforming (Elliott, 2011) is a method utilized in the act of creating any narrative such as a story or movie or video game where the reader or user of the narrative is exposed to some idea or concept early on in the narrative to set-up what is to come. Platforming is more than leaving a textual clue. It is setting up expectations. It is

introducing concepts. It is providing a vision of how you see the future unfolding. The difference in our platforming strategy was that unlike a movie producer or novel writer or game designer — we did not control the future. Our platform ideas became fictive imaginings of what we wanted the future to be. We hoped by framing what is, and projecting what would be, that we could communicate our visions of an inclusive future for Kenyon in public schools. When we wrote or spoke about the educators in Kenyon's life, it was never critical in the sense of listing a deficiency, but instead complimentary and future-focused. For instance, we would never say or write that Kenyon's teacher was an inexperienced and unprepared recent college graduate steeped in a modernist medical-model of disability but would instead frame the characterization as an optimistic and hopeful teacher full of energy and enthusiasm ready to employ the most recent theory and method toward creating the supports needed for all students to succeed. Platforming was a leap of faith.

Most teachers and administrators at the school were too busy with mountains of paperwork, too many responsibilities, not enough planning time, not enough resources, too many students, too many meetings, too many central office mandates, too much test-prep, too many emails, too much busy work to truly step back and perform the role of teacher as a thoughtful scholar capable of participating in critique and social justice transformation. Heck, salaries were stagnant, benefits slashed, co-pays rising, and the media culture driven by neoconservative networks, such as Fox News (Arin, 2013), created a teacher-bashing mentality transforming the iconic image of teacher as hero to

teacher as blood-sucking, government leech to be blamed for failing society. It's not easy being a teacher these days, my wife Janet can attest. Morale is low.

So, perhaps our expectations that teachers and administrators at Kenyon's school would be open to a radical transformation in the way inclusion was carried out in the classroom was too much to ask. But if we couldn't pull it off, who could? And if it couldn't happen here, then where? We had to try. We had to platform. We had to put our radical ideas out there. It had worked great for two years in pre-K as innovative teachers and administrators helped us imagine inclusion anew and build a new way of being in the classroom without labels. But Kindergarten was different. An effort was on not to critically examine and change the system for social justice, but to force us and Kenyon into the status quo.

> **GLIMPSE, Sept. 12, 2010, email to teacher, platforming:** I wanted to say thanks for your positive emails! We are very thankful to have you as Kenyon's teacher! You bring such a progressive, modern approach to education, which I know is a lot in part because you have an advanced degree, and that your teacher-education happened this century!
>
> Jan told me you said you were worried about writing to us about Kenyon. You don't ever have to worry! We know you are one of those special, rare educators who actually expect all students to make missteps in the classroom, and that you see those missteps for what they are - teachable moments! It is those teachable moments where education happens! Not only at school, but at home, too!
>
> So many old school teachers who are still stuck in teaching methods from the last two centuries would have not seen the possibility for learning, the potential for growth. Believe it or not, there are still teachers, even at our school, who keep detailed lists of so-called student transgressions or offenses as they "document" what they see as student failure. I see teacher failure, because those teachers still see students and families as the enemy and see teachable moments as inconvenient interruptions of their expected factory-like routine expectations of students to fit some old-fashioned mold of "normal."

> We are so happy to have a modern, professional teacher armed with the latest theory on learning, which positions these little kindergartners not as empty vessels to be filled by the teacher, but vessels chock-full of meaningful knowledge of their own that they bring to the table to be guided and led in learning by a caring, loving teacher who sees the value and potential of each unique student.
>
> I don't want us ever to get caught in the trap of negative deficit thinking, but instead focus on everything that has gone well and build on that success for the future, and to use our time together to talk about "how" and to celebrate our learning journeys. I know this is preaching to the choir. I know our successes together as student, teachers, and family will be too numerous to cover in such a short time together. You guys are the best! Take care, William Purcell

GLIMPSE, September 2010: I think Kenyon's teachers are already giving up on him. I'm giving up on them, too. This isn't going at all like I expected. Liam is in third grade. His first year for a high-stakes end-of-grade test. He is getting bored with test prep already.

Inclusion and Exclusion Hand in Hand

> A disturbing number of students with cognitive impairments receive much or all of their education in completely segregated learning terrains — separate classrooms, separate schools, sometimes even separate residential facilities or hospital environments…after decades of work seeking to include students with intellectual disabilities in general education classrooms, they continue to be segregated within educational communities, left off the maps of general education. What is going on? (Smith, 2006, p. 5)

My son Kenyon experiences a neuro-diversity that our modern system of education labels developmental or intellectual disability. If he or we ever desired supports in school through IDEA we would have to stick him with one of IDEA's 14 categorical labels — most likely mental retardation (though in October of 2010 the label changed to intellectual disability). I believe the label does not really fit outside of being a hegemonic key into the current system of domination that is special education services in schools.

Kenyon attended elementary school for two years in the More-at-Four pre-Kindergarten program. In 2010, he began Kindergarten. As a family, we have instituted our own version of a critical theory of education as Kenyon, and we as a family, moved through early intervention, transition, and special education school services. We quickly began to resist, defy, exit, redefine, and have begun to re-enter the schooling system in the spirit of Hegel:

> Our time is a time of birth and transition…the spirit has broken with what was…the spirit is never at rest but always engaged in every progressing motion..the spirit that educates itself matures slowly and quietly toward the new form, dissolving one particle of the edifice of its previous world after the other…this gradual crumbling…is interrupted by the break of day that, like lightning, all at once reveals the edifice of the new world. (as cited in Kellner, 2003, p. 51)

Confronting the school system, our family and our family spirit is constantly engaged in reframing, rethinking, re-imagining, redefining, confronting, and recreating what is, what can be, what is perceived, what is assumed, what is presumed, what is expected, what is thought, what is knowable, and what can be. We've kicked therapists out of our home, we've rejected paperwork, we've said *no* over and over, we've questioned teaching techniques, we've broken supposed *laws*, we've left the system, we've refused supports, we have bucked the system in favor of always what is best for Kenyon — rather than what seems best for the system, or what has *always* been done.

What we've been engaging in is what Kellner (2003) would call our own personal radical reconstruction and democratization of our personal educational situation. We have found our critical view of *what is* and the *way things are* in both the Greek spirit of

krinein and *theoria* (Kellner) — we reflect and judge and then move toward Kellner's new way of seeing. This has brought criticism from our county for *hurting its numbers*, because Kenyon was identified, but not served. This has brought criticism from teachers and administrators who think we should segregate Kenyon into a separate pre-school, separate elementary school, and in fact, a separate classroom completely that is more *appropriate*. Appropriate for Kenyon? No! For the status quo? Yes!

Kenyon's story and the story of his peers becomes a counter-narrative that reveals the anti-Deweyian principles at work in today's schools and perhaps signal the start of a slow death of our democracy because the narrative reveals what has always been true in America — that everyone does not have equal access to education, that participatory democracy for all is a pipe-dream, that unless Hegel's *lightning* strike occurs — we're doomed.

Students come to a public-school classroom with two key categories of resources I will define as traditionally-valued abilities and home capital. Traditionally-valued abilities are those physical, verbal, and even written literacies that pre-K teachers seek to increase in students as preparation for Kindergarten, eventual national testing, tracked school experiences, then entry into the outdated *modern* world of work or into the outdated modern world of higher education, and eventually to be dumped into a postmodern world woefully unprepared for the new digital age that we can only imagine will exist 12 years from today. A print-literacy emphasis (Kellner, 2003) was exemplified in Kenyon's pre-K classrooms where early interventions sought to put books in students' homes, guilt-trip parents into reading with kids, reward pre-reading skills above all in the

pre-K setting, and center almost every aspect of the class on the development of a traditionally-valued ability — physical, verbal, and written — three areas that were not the strengths Kenyon brought into the classroom, but he did bring others. The written is highly privileged in terms of money spent on books and on the physical arrangement of the classroom, which creates learning centers around books, letter carpet squares, *Letterland* characters and puppets. The lack of technology is astounding. There are two computers — one for the teacher, one for students. There is no Smartboard, no data-projector, no speakers, no operational TV (though there is a TV mounted in a corner that features a clock — waste of energy). For Kenyon, or any other student, there are no iPads or iTouches or iPods or any other device that would supplement the technological emphasis that they are likely to need in their future globalized and technology-saturated world. Like the written literacy efforts that are easy to see in operation, the verbal literacy efforts are easily seen also as students sing, listen to books read aloud, and listen and repeat what the teachers says. However, it is worth noting that only verbal and English literacies are valued. My son who communicates with sign language and his friend Guillermo [name changed] who speaks Spanish entered class at a distinct disadvantage because their strongest modes of literacy were not valued in the classroom. From the start, they were excluded. Instead of adapting the classroom to speak ASL and Spanish in addition to verbal English, the primary mode is to force instruction into the narrow box of English-only instruction.

As I move to an example of traditionally-valued ability in regard to physical nature, I want to introduce what I call home capital. Home capital is the type and amount

of resources provided to a student at home from books to computers to English-speaking parents. All home-capital is based on the traditionally-valued abilities that schools emphasize. So, my son's peer Guillermo who comes from a family rich in Latino cultural-capital and Spanish language skills, has little home-capital grounded in traditionally-valued ability. Guillermo has no books, no computer, no video games, none of the technologies, which puts Guillermo on the poor side of the digital divide. Guillermo's first experience with a computer is in the pre-K classroom where he is paired with my son Kenyon who does not possess the traditionally-valued physical abilities to use a computer, but who has the home capital knowledge of a computer. Guillermo is strong in one traditionally-valued ability at school — physical ability. Kenyon knows where the pointer goes — to click on start, then programs, and on and on to navigate through the school's awkward interface in order to access games, the Internet, and resources online such as *Letterland* games. Kenyon knows how the games work. Kenyon understands the concepts of windows. Kenyon understands layers and windows and how to click through them. Because Kenyon comes from a family that uses computers and helps him use computers, and because his mother teaches at the school and has exposed him to the school's computer system — Kenyon comes to school with high home-capital. However, Kenyon does not have the traditionally-valued physical ability to manipulate the mouse and the keyboard. Guillermo has the physical ability, so together the two are a perfect match. Kenyon points where to go on the screen and Guillermo follows his finger using the mouse. Kenyon is teaching Guillermo how to use the computer.

One part of me beams with pride in that my son with a so-called intellectual disability who is *nonverbal* and *physically deficient* in the cold, modern lens of assessment is teaching a peer — something no other pre-K student is doing. Kenyon has dismantled the slave/master concept of teaching (Behnam, Azimi, & Kanani, 2017) and found a path to learning that is collaborative, empowering to both parties, and independent of his master/teacher. At the same time Kenyon is teaching Guillermo, Guillermo is teaching Kenyon about how the mouse works and the keyboard. His physical skills are improving with interaction with Guillermo.

Is it any wonder that Guillermo and Kenyon were best friends? They both were marginalized by the educational system. They were both included in that they were in the same room with everyone else. But in that act of inclusion, they were both excluded because the classroom, the school, the teachers, and their peers' privilege singular ways of being and belonging in school. Both come into a classroom that is not focused on their individualized supports and valuing their own personal cultures, but one that works as Kellner describes Freire's notion of schooling as, "a form of indoctrination, of enforcing conformity to dominant values, and of social reproduction in which one is tutored into submission and accepting an oppressed and subordinate status" (2003, pp. 55-56). The school tells Kenyon and Guillermo that you must abandon your cultural capital and assimilate into our system that will school you to speak and write English, so that you can learn about our white English founding fathers, perform as well as you can on our tests, so that we can track you into educational lines that put you in a class of rulers or a class of servants.

In contrast, there is a peer in the pre-K class that comes to school with both a complete set of traditionally-valued abilities and home capital. Jim is already ahead. He is already immersed in the technologies of this millennium. He only speaks English and speaks it well. He already knows the American cultural stories that will be tested from the stories of Pilgrims to Washington cutting down the cherry tree to the tunes of *School House Rock*, which his parents bought him on DVD.

So how do we create a new path to avoid "some communities or individuals in privileged groups" being "exposed to more advanced technologies and given access to more high-tech skills and cultural capital than those in less privileged communities?" (Kellner, 2003, p. 62). How do we break free from the monoliths that are our schools that track students? How do we break free from modern schools in a radical way? How do we disrupt inclusive education that becomes open exclusion?

> **GLIMPSE, September 2010, journal entry:** We were able to put off the referral meeting because there was no hearing or vision screening done first. And no written notice prior to hearing/vision screening, too. But it seems they are determined to force Kenyon into special education services.

She Put Him in a Pumpkin Shell

During Kenyon's first progress report in kindergarten the teacher told us they assessed all the students on lower and uppercase letters. She pushed a blank sheet of paper across a table to us. I didn't get it. "Ok, what's this?" I asked. "This is what Kenyon knows," she said. Bite tongue. Grip knee. Hold back. "Really?" I asked. "Yes, he didn't know any of the letters, so we've got a long way to go," she said matter-of-factly. The

rest of the meeting didn't go too well either. It was clear to us that the teacher had no clue how to assess Kenyon.

That night Janet spread out a letter puzzle on our living room floor, set up a video camera, and asked Kenyon to find each letter. He found all but three. We uploaded the video online and sent a link to the teacher and the principal. Two weeks later when we met to review Kenyon's report card, the assessments showed Kenyon knew 24 lower-case letters and 21 upper-case letters. Tongue firmly planted in cheek I said, "It's amazing what you taught him in just two weeks." I shouldn't have said it, but I needed to say it. The first assessment was clearly a result of deficit-thinking, which Valencia (2010) describes as, "tantamount to the process of 'blaming the victim'…a model based on imputation not documentation" (p. xiv). The problem was not Kenyon, but the imputation of the assessment that didn't measure his ability but revealed the bias of the assessor. She couldn't see past her image of what Kenyon could achieve. She couldn't see Kenyon as a child who knew more letters than several other students in class. She couldn't see Kenyon as capable of learning. After the video incident, the teacher really began to try to teach Kenyon. And she had many successes. But still deficit-thinking kept slipping into how teachers thought about Kenyon.

In October, Janet stopped in the classroom to observe. A lesson was being held with everyone on the floor crowded around a poster of the *Peter, Peter, Pumpkin Shell* poem. The teacher asked children to point to various words in the poem using a stick with fake hand on the end. Janet signaled to the teacher to let Kenyon try. "Where's pumpkin?" she asked. And he pointed to it. Afterwards, she told Janet, "that was really

amazing!" Janet asked, "well, surely he's pointed out words before today?" She said, "no, I've never asked him before. I didn't know he was capable of doing it."

> **GLIMPSE, October 2010:** The teachers and administrators at Kenyon's school want to force us into special education services. We refuse. We know the goal is to get him out of his local school and into the one "special" school in town. All the teachers see is disability. They never welcomed him into class. He has really been treated as a second-class citizen from the start. We are staying the course.

The National Deficit — Thinking

People don't see Kenyon's shunt. If you rub his head, you'll feel it. It keeps him alive. It allows fluid to drain off his brain and travel through tubing around his ear, down his neck, and into an area around his belly where it is released and reabsorbed into his body. The neurosurgeons coiled the tubing inside him so that as he grew taller it would uncurl and stretch and still release the fluid in about the same area. He still has a horizontal, snow white scar on his belly. But people don't notice it. What people notice first is his walk.

He wobbles from side to side as he walks. He has a stutter step. One foot rises up higher than the other. He likes to high-step. Then people see his face. What do they see? They see the other. They see wide set, slanted eyes, and think, "is he Asian?" Strangers, acquaintances ask, "Where did you adopt him?" I never can figure out if they think he looks like he is from another country or if they assume that a couple like us would have aborted him. But the assumption is the same — who is this *other* and where did you get him?

I can forgive ignorance and stupidity. But what frustrates me most is deficit thinking (Valencia, 1997). When Kenyon walks into a school, a classroom, a camp, a lesson, a seminar, anywhere there is a *teacher* who labels him as deficient from the first look. In public school, deficit thinking was so entrenched into the established routines it became impossible to interrupt and rupture the status quo. Yet, we tried. From the get-go his teachers used words like retardation, delayed, disabled, deficit, impaired, behind, and identified, though there had been no assessment. From reading the visual cues for Down syndrome, they assumed they knew him and his capabilities and potential and limitations because they had read it in a book in college, or watched *Life Goes On* or had a cousin with Down syndrome. Everyone has a cousin, and everyone wants to tell you about it. But they don't know shit.

Down syndrome is not a monolith, but schools treat it that way. Down syndrome is one part of who Kenyon is, but over and over people saw him as "he's Down syndrome" or a "Down syndrome student." Ironically, no one ever talked about his hydrocephalus, which probably had more of an impact on his learning than Down syndrome. But people couldn't read hydrocephalus, or peg it, or stereotype it, and no one had a cousin with hydrocephalus.

In school, Kenyon would always be what people saw on the surface. The parent who asks the teacher, "why is the retarded kid in here with my kid?" The teacher who didn't respond "he's not retarded," that didn't respond "please, don't speak that way, it's offensive," but reified the notion of retardation by responding, "we include all students here." We fought to create a new way of including Kenyon in school, but the

establishment worked even harder to maintain the status quo. No one wanted something new. The fight was to get you into the system as it existed at all costs. No one wanted to talk about fixing the system, in fact, no one wanted to talk about the system at all other than how to fit into it. No one wanted to talk about questioning the system. No one wanted to think about alternatives to what had always been done. It all came down to *this is the way it has always been done*. And the message was clear. Do it our way or get out.

> **GLIMPSE, October 2010, email to William from Janet:** There is this rainbow thing in Kenyon's classroom where teachers add a piece of rainbow behind your name whenever you do something nice. Sydney and Sierra were looking at their rainbow. While they were there, Sierra noted, "Kenyon doesn't have any rainbows." I asked them, "Does he do nice things sometimes?" While Sydney was saying yes, Sierra took two or three pieces of rainbow and put them behind Kenyon's name.

One Bad-Ass Motherfucker

> **GLIMPSE, around 2010, essay written for graduate class:** I have come to the unfortunate conclusion that significant meaningful change will not come from inside the system. Special education, service providers of all types, and the legal system have all conspired to create what we have now, which keeps those extraordinary individuals who experience disability mired in a system of oppression that reduces lives to assessments and labels in order to receive the supports necessary to survive in world designed to benefit the ableists who don't even realize their invisible web of privilege.
>
> Change must rise from within the ranks of the extraordinary people that society labels disabled, and all advocates must join with, and self-identify with this movement because we all live in temporarily-abled bodies, and if we are lucky enough to live long enough, all the so-called "able-bodied" people will join the proud ranks of those experiencing disability. Disability is the one label, the one minority, the one identity group, that we all either belong to already, or can one day, or will one day join. It is a truly fluid identity. We all experience disability, whether you want to label it that way or not.

I experience disability through my son. I experience disability as I care for him, as I sign with him, as I interact with a myriad of health-care providers, as I fight for his inclusion in school, as I walk with him anywhere and the people stare, gawk and gape — and oh how they do. I experience disability walking with Kenyon finger in hand as people come up to us to share their unsolicited stories about their cousin — everybody has a cousin like Kenyon. The less tacit folks ask, "Do you mind if I ask what's wrong with him?"

What's wrong with him? What's wrong with you asshole? I experience disability as anger, pain, and rage as we walk together finger in hand watching the world watch us. I experience disability as I sit with Kenyon watching *The Daily Show* on the DVR and someone on the TV show lets loose with the R-bomb "that's so retarded"; as the well-meaning relative says "it's like having a baby all your life," and I'm thinking — Kenyon is going to grow up to be one bad-ass motherfucker and put an end to this stereotype of the happy disabled kid. I hope Kenyon slaps some kid in school and gets sent home. I hope he spray paints *Teachers Suck* on the bathroom wall.

Why happy? The stories people tell me fall into two binaries: either the super crip (McRuer, 2006) story or the pity story (Shapiro, 1994). I never ask, they just tell me about their second cousin who hiked the Appalachian Trail in a wheelchair or about their other cousin who died because he looked the wrong way when crossing the street. "Yeah, he was such a smart, outgoing, creative, happy guy…too bad he was retarded." Fuck you. I'm tired of your cousins. I'm tired of your stories. Shut up and let us walk through the store without burdening us with your piss-ass story of pity or overcoming.

I experience disability not only through my son and his life, but as I drive around town with the "handicapped" hangtag swinging from the mirror like an albatross. I pull in a regular space and get strange looks like "Why is he taking up one of our regular spaces" or "He doesn't look disabled, why does he have one of those tags?" I experience disability riding around with my friend who is a wheelchair user searching for a spot to park because someone parked in the accessible space for "just a minute." I experience disability traveling with my friend Jim who experiences disability as blindness as we get drunk at a bar or navigate a movie theater — yes, blind people like drinking and movies, too. Though I experience disability in multiple ways, I, like millions upon millions of others who experience disability through people in their lives that they love, call friends, live beside, or work with, don't self-identify with disability. Why?

Because of our comforts in the privilege of ableism? Because secretly we can't let go of what society has taught us about disability? We must stand together and declare ourselves part of one disabled community and fight for equal rights,

because if we don’t, if you don’t, then the day you will have a child born with a congenital disability, the day ALS or MS or some other abbreviated disease begins to change your body, the day the years catch up with you and you start to use a cane or crutch or chair for mobility assistance, the day you are in an auto accident — the day will come when we all join the ranks of those extraordinary people who experience disability.

If we don’t fight now to change the systems of oppression, if we don’t advocate for better access, equitable opportunity, accepting and embracing attitudes, for universal design of structures including curriculum, instructional design and building design, if we don't join now, then when we are forced into the one fifth of the United States that experiences disability, it will be too late.

Change is going to come from the people, not the system. It is going to take action. It is the extraordinary people experiencing disability joined by advocates from parents to relatives to neighbors to coworkers to friends to whomever is willing to join the cause to say I am part of disability culture, I am disabled, if not disabled in the typical sense at least disabled by the treatment of my brothers and sisters or disabled my my own experiences of and with people experiencing disability.

My son is in school, but not in special education. At some point the school is going to try to force us to assess him, label him, and begin to incorporate him into the system of oppression that is special education so that his IQ can be calculated, his potential therefore determined statistically, his curriculum watered-down, oops I mean modified to show and repeat, show and repeat, and all of it measured and followed through a medical model that emphasizes that the problem is Kenyon, and we’ll all write IEP goals that focus on changing Kenyon to as close to "normal" as possible, and eventually he will be segregated to a separate school where he will be in a separate classroom, where good-intentioned teachers will feel really good about themselves because they are helping this pitiful person develop some life skills that will allow him to join his peers after leaving school at 21 to take a job in either food or filth since those are the primary two jobs available to those with cognitive differences.

We all have to become like my dream of Kenyon as a bad-ass motherfucker — go against the grain, make people uncomfortable, asked the unasked, say the unsaid, break the rules, don’t worry about other people’s fragile feelings.
My family is headed down a path of due process. I’m sure of it. We have the resources to at least hire an attorney for a while. Perhaps a judge will ultimately say that we have to submit our son to an IQ test and enter him into the special education system, and we lose on appeal. Then we will pull out.

But perhaps we will be the ones that change the system, perhaps we will be the ones that turn the medical model on its head and changes special education from focusing on what is wrong with the person experiencing disability to a system focusing on what is wrong with the system.

Asking why isn't the system providing the appropriate supports for this student to succeed? What is the teacher or the school or the principal not doing all that they should be doing to ensure that this student succeeds? What are the external factors that are preventing this student from succeeding?

I have a dream, too; that separate is never equal for students experiencing disability. People experiencing disability are not broken, they are not abnormal, they are, we all are, and will be, extraordinary bodies and minds, extraordinary people, who experience disability.

GLIMPSE, Fall 2010, email William to Janet: Have you seen this contest the school is doing to collect box tops for education? They've got two giant glass jars in front of the office. One labeled boys and one labeled girls. If the boys collect the most the school gets a dress in camouflage day. If the girls collect the most the school gets a dress in pink day. OMG!

For real? I guess this is a battle we don't have time for, but what are our boys learning about gender in this school? Liam used to love to dance, now he hates it. Liam used to want to have playdates with both boys and girls, but now he keeps talking about how bad girls are, "dogs rule, girls drool." Liam has learned to hate pink. Why?

What if they find out Kenyon plays with dolls? I'm worried about what school is turning our sons into. They spend more than six hours a day there. I feel like we're losing them.

Walking on Blue Lines

Kenyon's school had two feet of blue tiles on either side of every hallway that formed dividing lines between where students were allowed to walk. Students were to stay on the blue lines and out of the white tiles in the middle. Only adults could walk off the blue lines. Blue lines became an issue of contention for Kenyon and his teachers.

Since his mother taught at the school, Kenyon knew everyone and everyone knew Kenyon. When Kenyon saw a person he knew in the hall he left the blue lines to hug them. With time, I knew Kenyon would understand and learn to stay within the lines. I volunteered in school three days a week. I began to notice how often teachers were shouting in the halls "stay on the blue lines" or "no playground time, if you don't stay on the blue lines" or "when the bell rings that means get on the blue lines." It wasn't just Kenyon. All the kids had trouble with it. At least in the younger grades. The older students filed by quietly and obediently staying on the lines. They had learned!

I drove two hours to visit a friend of mine in prison. I had been inside prisons before, but it had been a long time and this was a brand new facility. From the outside it could have been mistaken for a school. Same brick, same windows, same minimal landscaping, same basketball goals and bleachers behind chain-link fencing. The only difference was the spiraling, razor wire at the top of the fence at the prison. Inside I had the same experience: same concrete walls, same drab paint, same tile floors, same institution vinyl-covered furniture, and even the same secretary at the entrance asking you to *sign in* and giving you an official *visitor's pass* to wear.

We lock children away for six hours a day (nine hours if the student does before/after school program) just like prisoners warehoused in a prison industrial complex where every action is monitored and controlled, only in schools it is under the banner of freedom and illusion of democratic practice. Schools, just like prisons, operate in a patriarchal hierarchy where the students and teachers become robotic automatons

under constant surveillance and control from what you do online to when you can have a bowel movement to who you are allowed to hug when and where you should walk.

As the prisoners filed into the next room behind the glass, I spotted my friend and waved. He caught my eye but didn't respond in any way. He kept his head straight, walked in line, and waited for the guard who called out, "behind the red line, gentleman, until I give you the signal. Then you'll have 15 minutes. When I ring the bell, you will return behind the red line. Understood?" In unison they responded, "yes, sir."

> **GLIMPSE, November 2010:** Inclusion in what? Why are we fighting so hard for inclusion into a system that works to exclude even in inclusion? It's clear Liam is being turned into a different child than he was before public schooling. Test prep, immersion in peer culture, and the monotony of routine are changing him into a robotic automaton who can obediently regurgitate so-called facts on cue, but do little, if any critical thinking.
>
> Reading is now a chore for him. He's learning rigid gender roles. He is beginning to value the corporate icons and the consumer culture that is the focus of many of his peers.
>
> It's clear the school wants Kenyon out of the regular classroom unless he is fully identified, labeled, and funded through IDEA. He has become a commodity whose inclusion depends on funding, not on his right to be there or his value as a human being. The teachers see a child that needs fixing. We see a school that needs fixing.
>
> I fear for his safety. The teachers are keeping lists, documenting, and setting him up for the failure needed to justify his exclusion. Big meeting later this month to sort it all out. The four of us against a team of 20.

Hand in Cap

The school had just finished a major reconstruction of the entrance and had three great big new accessible spaces in front of the school. A big improvement. However, the

construction left the lower lot without any accessible spaces. This meant there was no way to access the lower portion of the school without entering at the top and using an elevator to move to the bottom. This meant the playgrounds, the ballfields, the walking track, the basketball courts, the playground, and the picnic shelter were all inaccessible from the lower lot. I saw the principal in the parking lot and thought it would be a good time to talk about it.

A simple solution would be to transform a couple spaces in the lower lot into accessible spaces, which would only need signage. The response from the central office had always been that the lots met the requirements of the law, though in practice it still left a huge portion of the school and grounds inaccessible to students, parents, grandparents, community members who wished to use those parts of the school. I gave my pitch. He said, "you mean the handicap spaces?" I said, "No, we don't use the term 'handicap' any longer." I got off on a tangent about the etymology of "hand-in-cap" and how people-first language was important to creating an inclusive society, but I eventually got back around to the accessible spaces.

"So, you want a new handicap space?" he asked again. Argh! "Yes, can we put up a sign in the lower lot for at least one space?" I asked. He responded, "I've looked into it, and it meets the letter of the law we only have to have three handicap spaces and that's it." Argh! He added, "And we don't have money in piles just to go spending on signage that isn't required by law." Got 'em! I said, "But you found money for that new *School of Excellence* banner in the entry. A new accessible sign would be a fraction of the cost of

that banner." He frowned, "I'll look into it." To this day, there is still no accessible space in the lower lot.

> **GLIMPSE, Day of the Big Meeting, 2010:** Snow. It will take another month to reschedule these 20 teachers and administrators again. We've been able to put off the referral meeting over and over due to simple errors by the school. They didn't conduct simple screenings or notify properly or complete the appropriate paperwork. They won't be able to reschedule until January. This means Kenyon can stay in kindergarten through the end of the year.

Exceptional Students

Any support Kenyon needed in the classroom seemed to require a Herculean effort from the teachers. This is an extreme contrast to our experience with Liam, in which those same supports were given freely, happily, and with much praise and fanfare from those same teachers. Supports were given to Liam even without us requesting those supports. Teachers left their classrooms to go to a higher grade-level to pick out books for Liam to read because the books in his classroom were too easy for his reading level. Liam's teacher requested that the gifted and talented teacher come teach him, so she did come into his classroom to give him extra instruction because he had mastered the concepts the regular teacher was teaching to the rest of class. The teacher thought of activities just for Liam like allowing him to lead a team to build a race track over the course of several days. Though there was no qualification process, no identification, no labeling, Liam was receiving the supports he needed to succeed without any request from us, without any complaint from the teachers, without any funding attached to his need for those supports.

Yet when Kenyon needed those same supports, those supports became burdens, just as Kenyon became a burden. The teacher could not support Kenyon unless he had a label, unless he had been identified, unless there was specific money tied to those supports. The teacher didn't have time to get appropriate books for Kenyon. The teacher didn't have time to do anything *different* for Kenyon. What does all this say about how one life is valued over another life? How one student is valued over another student? The striking contrast in how our two children were treated by the school illustrates how schools value children.

Though most teachers, principals, and school administrators at the central office would vehemently deny that students are valued differently, our experience illustrates that there is a division in how students are treated. Those who would qualify for funding through special education must go through that process and any supports they need must be funneled through that process. Those like Liam who were perceived as *advanced* get natural supports in the classroom provided by their primary teachers. While it is true Liam would eventually be screened out and offered services as an exceptional student in the so-called *gifted and talented* program, that did not kick in until third grade at his school. However, in his three years pre-K through second-grade, his teachers bent over backwards to modify, accommodate, and support his unique learning needs with no label attached. When we asked for the same support for Kenyon without a label, without going through the special education process, with only the same treatment they gave Liam — the answer was a resounding *NO!*

Safe Space

To welcome all students, is that too much to ask? To love all students, is that too much to ask? No one ever welcomed us or Kenyon to school. Our interactions at school were always about what was wrong, what went wrong, what we need to do, what Kenyon needs to do. It was always about how we or Kenyon needed to change. Trying to convey the idea that there was nothing inherently wrong with Kenyon, that Kenyon was not in need of fixing, that all Kenyon needed was simple supports to succeed — it all seemed inconceivable, unthinkable (Britzman, 1995) to the teacher, to the principal, and to the school.

There was only one group of people who truly welcomed Kenyon into the school with warm, open, and loving arms — the custodial and cafeteria staff. The cafeteria workers in particular broke rules and routines to make Kenyon's cafeteria experience positive. They greeted and welcomed him. They made sure he made it through the line with no trouble. They attempted to learn signs more than anyone else. They hugged. They loved. The wanted him there. For Kenyon, the cafeteria was always a safe space. The custodial staff too, made extra efforts to know get to know Kenyon and check on him. They would act as surveillance officers for our family, often letting us know when they saw something that made them think something was wrong. Kenyon shows his emotions on his face. When the custodial staff saw negative emotions on Kenyon's face, they made a trip to Janet's room to let her know. We didn't always follow up so to give the teachers space, but it was comforting to know we did have allies on our side. It's ironic that the

very folks who were most supportive of Kenyon in school work in professions that people with developmental disabilities tend to work in - food and filth.

When the hallways, classrooms, gym, and music room became battlefields of surveillance where his actions were documented in order to regulate him into the expected order in the oppressive regime of special education services, the cafeteria remained the only safe space from judgment, documentation, and regulation. Kenyon could be himself. Kenyon could be welcomed and loved and supported without paperwork or labels. Those cafeteria and custodial workers were among the best teachers in the whole school.

Manifesto of Support

We wrote a manifesto to describe the new vision of supporting Kenyon's inclusion in school as a way of articulating our goals for his inclusion and his education. Of course, this conflicted with what had always been done and what was expected to be done. This manifesto was what Britzman (1995) would call *unthinkable*. The concepts were so foreign and unprecedented that even comprehending the language was difficult, much less seeing or implementing the vision. This too, was an effort in platforming:

- **The Fluid Nature of Life:** We first and foremost want to recognize this document as a living, growing, and changing representation of our articulation of the learning journey of Kenyon, us, and the entire community of support around our family and school. It is a starting point. It is something that will evolve as we evolve. It is a recognition that we all are learners.

- **Purpose:** What is the purpose of this document? We have discovered over the course of six years interacting with those involved with Kenyon's care that sometimes there is not time to communicate in a deep and meaningful way in the course of a face-to-face meeting. We believe by articulating our basic thoughts about Kenyon, our family, and learning, that those in Kenyon's community of support can more deeply understand each other and work together to support Kenyon's and our own learning journeys. This document is also a way for us to continue our own personal praxis as educators and as parents and as contributing members of the school's community of support.
- **Tradition is the Enemy of Progress:** The traditional model of special education set up by decades of litigation over state law, Section 504 and IDEA gives us a system today that pits families against the school system in a grand negotiation to interpret language, law, and policy in order to provide basic education services to students. The system is set up to be confrontational. The system is set up to lead families and school systems to take sides and fight it out in person before moving on through due process. Though we are equipped as veteran educators; though we have the knowledge of law, policy, and the system; though we are strong disability rights advocates; though we have the money, the will, and the ability to work through, confront, advocate, fight, sue, and take any case through to its bitter end — we reject this entire narrative that has been handed us and the school system as the only script. The way it has always been done doesn't work. We

don’t have to accept "what is." We don’t have to follow the script that has been written and handed to us all. There is a different way.

- **To Do What is Right:** We envision a classroom, a grade level, a school, a school system, a community, and a home from which students, teachers, staff, administrators, community members, and parents embrace the challenge to meet the needs of every student in their local school because it is the right thing to do. We reject the notion that education must be justified, commodified, and divided through labels, job descriptions, budget lines, law, policy, and tradition. We envision a community of support around all students that works creatively, openly, and passionately to do what is right. To do what is right because it is the right thing to do. To do what is right, even though it is not in a job description. To do what is right, even though it doesn’t come from a certain budget line. To do what is right, even though it is not the easiest path. To do what is right, even though that’s "not the way it has always been done."
- **Our Community of Support:** We envision a community of support rising up around Kenyon. In fact, it already has. Kenyon’s friends, students across grade-levels, teachers, librarians, secretaries, principals, central office staff, cafeteria workers, bus drivers, other parents, us, his brother, people in our community and in disability rights communities statewide and nationwide, people at our local college and the University of North Carolina at Greensboro — this wide-reaching community of support already knows Kenyon, and has taken, is willing to continue to take responsibility for helping with Kenyon’s education.

- Kenyon’s brother helps with his homework and translates signs; a librarian ordered books featuring students experiencing disability to make the library truly more diverse and representative; cafeteria workers give love and attention making the loud, boisterous cafeteria a warm and welcoming place; teachers think about "how" and not "if," like providing a motion-sensor soap dispenser or adding a *pull* to his lunchbox, or dropping lesson plans to improv exploring natural questions that pop up like "why doesn’t he speak?"; central office staff allowed Kenyon a second year in Pre-K, bought a humidifier for the class, and continue to support inclusion over segregation; parents who encourage their children to use sign and who include Kenyon in activities outside of school; peers who joyously learn alongside Kenyon provide a hand up when he falls, and he provides a hug when they are sad; principals who work to lead and create a school environment that truly values the worth of every human being, and recognizes the importance of the qualitative stories of what happens in the classroom over the quantified measures of a once-a-year test score. Because we have a community of support and willing, progressive educators at this school, we have the opportunity to be a model learning community for all students, including students experiencing disability.
- **Our Vision:** Our vision is simple — education is a birthright, not a privilege. We believe every child has a right to have all learning supported alongside peers at a local public school. For our family this means that Kenyon’s learning will be facilitated through his community of support in the typical classroom alongside his peers at school through his graduation because it is his birthright, and because

it is the right thing to do. We are creating a model learning community built on the cornerstone that schools should NOT be a mirror reflecting "what is", but a lamp shining as beacon to all of what "should be and can be." We are saying that sporadic report cards, test scores, and cold numerical assessments are secondary to the on-the-ground daily assessment of real human minds, bodies, and spirit that school teachers, staff and principals love, care for, and lead in learning on a daily basis.

- **We Believe:** We believe that when a child's natural interests are tied into his learning environment it leads him into learning in a way that expands his interests. We believe a child should never be measured by perceived deficit. All children should be measured by strength-based assessments. It is most important to know what a child can do and build from that foundation. It is not important to know perception of what a child supposedly "can't do." In fact, deficit-based assessment leads to deficit-thinking, which allows the oppression, domination, and skewing of reality for many marginalized groups including those experiencing disability. We believe that inclusion can quickly become segregation in the open with sentinel-like teaching-aids hovering over a child, marking that child as the other, and separating that child from the group.
- We will not seek special education services. We believe therapy should be provided outside the school setting and will seek it through private insurance and private practice. We do NOT want any assessments performed on Kenyon without our written consent. This includes medical assessments from vision to dental

screenings. Kenyon regularly sees pediatric specialists for screening and support in dentistry, ophthalmology, neurology, orthopedics, and his local pediatric specialists. If you would like assistance in a strength-based assessment, we would be happy to provide that support.

- **You are Not Alone:** We know Kenyon better than anyone on the planet. Please use us as resources. Kenyon's educators are not alone. And we are educators, too. We love brainstorming, talking shop, and exploring ways to design instruction and facilitate learning. In addition, there is an entire community of support around Kenyon that we can access their wealth of knowledge.
- We clearly wanted to approach inclusion differently than it had ever been done. Many teachers and administrators nodded and smiled and pretended to go along. But behind closed doors a movement was afoot to shove our vision aside and force us into the system as it existed. Emails became passive-aggressive. Teachers began documenting everything in writing. Lists were kept. Meetings without us were held. It became clear quickly that no one really wanted to try our plan. The underbelly of the system was working to get us into pre-referral for special education services as quickly as possible. We never imagined that people wouldn't help us. We never imagined that people wouldn't try. We never imagined that we couldn't overcome the obstacles in our path. Kenyon was not a typical student at the school. Historically, children *like him* were shipped off to one central school in the system where they were all segregated from other students. We knew from the start that we had the resources and abilities to pull

out of public school and homeschool, if needed. But we never imagined that was a real option. To us it was a matter of how, not if. We were wrong. We were so damn wrong.

Inclusion is Not the Answer

We were fighting for inclusion. Inclusion in what? A gendered, sexist, racist neoconservative, potty-mouthed, bully-filled, media-saturated school culture? Why are we making all this effort to be included? Is this really a place we want to be? It became clear to us that unless Kenyon was attached to funding through IDEA that no accommodations would be made for him. It became clear that the ultimate goal was to move Kenyon out of the neighborhood school and segregate him to the central school. It became clear that Kenyon was not welcome. But it wasn't just Kenyon.

Liam was becoming a robotic automaton trained like a circus animal to regurgitate the one and only correct answer on a high-stakes end-of-grade test. And since he was a likely candidate to pass, he was receiving little attention other than keeping him busy, while the teachers focused on improving the numbers of those at-risk to not pass the test. But not the ones at the *bottom*, they were really only concerned about moving those right on the border of not passing. That left Liam with daydreaming, making paper airplanes, and finding trouble because he was bored to death in school.

The school social arena was training Liam into becoming a homophobic, heterosexist, misogynist who valued commodities of coolness of what the crowd was doing versus the private passions he had loved, loved until kids told him on the

playground, bathroom, or hallway that singing is for girls, or sewing is for fags, or that music is for sissies. School culture was introducing Liam to the topics of third-grade boys: violence in video games, racy themes on TV, and the value of commodified pre-packaged culture of Chuck E. Cheese, Nike, and Disney. Boys wore camo and girls wore pink. Boys like guns and girls liked Barbies. Killing games and war games were fun. America is great. Arabs are evil. Cheer the death of terrorists. Real men loved Jesus. Parents suck and don't know shit.

Liam was learning how to be everything we tried to teach him not to be. We kept him out of daycare to give him a stay-at-home parent. We limited TV to PBS or pre-approved videos. He had never seen a PG or higher rated movie. He didn't hear the news or snarky radio DJs. We didn't sit him down in front of Disney movies as a babysitting tool. We exposed him to art museums and Broadway shows and classical music and bluegrass. Yet, after turning Liam over to public schools, it seemed everything we had done as parents to give him an open, accepting, and loving world view, was being replaced by the very ideologies we sought to prevent. We had worked our entire adult lives in education and always supported public schools, always wanted public schools to succeed. But the choice in front of us was clear — inclusion of either of our children in public school was not the answer.

Now That's Fucked Up

The total lack of relevance and meaning in the activities asked of Kenyon at school became a huge factor in choosing to homeschool. If not sitting him in a corner alone, they would struggle to find him anything meaningful to do. It's easy to blame

Kenyon or us as parents for resisting bringing in a full-time aide for him, but we weren't bringing in a full-time aide for Liam and he was just as troubled with finding relevance and meaning in school. Liam was smart and excited about learning, but as he moved through the grade levels you could see that fire of learning being extinguished.

At Liam's last parent conference before we deschooled the teacher told us, "the problem with Liam is getting him to sit still and not blurt out the answer." She told us he was *too eager* to answer questions and explain concepts. That he wanted to act and experiment and suggest things to do — to explore the topics, but it often didn't fit into the plan. We understood. In a class of 30 students one student shouldn't dominate the discussion. School in particular ran on a rigid schedule. And the teacher couldn't modify every assignment just for Liam, right? But why not? Shouldn't she? Shouldn't every child's learning be individualized? What was the alternative? Sitting on his hands? Daydreaming? Becoming as bored with class as Kenyon was with his?

One thing Liam did learn — obedience. Walk on the blue line. No touching each other. No talking. Eat quickly. Play fast we only have 20 minutes out here. Listen to all the instructions completely before you begin. Don't build paper airplanes. No you cannot tell a story. Do not help your neighbor.

Students used manilla folders as room dividers on their desks to keep their neighbors from cheating on EOG test prep. Each student got two folders and built a mini-fortress around them. When finished you had to sit quietly and wait for the timer. Liam didn't want to sit and and wait, or even sit and listen, he wanted to build, to play, to

explore, and to interact and act. Liam had a friend who struggled. I asked him why didn't he help him? Liam said, "it's cheating to help another student."

Liam brought home EOG prep packet after prep packet after prep packet — reading through we began to realize how little value the "facts" are that were being drilled into him. Helping Liam with his homework one night I drilled him on a list of *facts* about weather he was supposed to memorize — water boils at 212 degrees…70 degrees is hot…40 degrees is cold…water freezes at 32 degrees — wait a minute, 40 degrees is cold? I told Liam this wasn't true, not really. He disagreed saying, "if the worksheet says it, it's true." But if you live in Florida and are 90-years-old like Grandma Heath then 70 degrees is quite cold and 40 degrees is unbearably freezing. "No Dada, 40 degrees is cold, 70 degrees is hot." But, here in the mountains of North Carolina 40 degrees is not cold to us, but to your grandpa down at the coast of North Carolina it sure is, right? "No, you're wrong and the worksheet is right, now keep quizzing me." But Liam, in the late Fall before winter starts, our first 40-degree day feels extremely cold, but in late winter a 40-degree day feels quite warm, right? "Dada, you're making this too complicated. Facts are right or wrong. If it is right you get a check-mark and if it is wrong you get an X-mark, ok? This is simple." But it wasn't.

Liam was becoming a little robot programmed to perform extraordinarily on an 88-question test. Where was my critical thinker? Where was my musician? Where was my actor? Where was my artist? Where was my child? What had public schools done with him? The debate over 40 degrees became a tipping point. It pushed us over the top of the hill and our thinking snowballed toward something different — toward escape,

toward healing, toward something new. It had happened to us before with Kenyon after a CDSA therapist asked us to withhold food from Kenyon until he tapped this big red button that beeped much like a Staples Office Supply *that was easy* button. She called it *Sabotage Therapy*. We called it, well, a phrase we learned from disability activist and best-selling author Steve Kuusisto who said, "Now that's fucked up" (Purcell, 2008). Kuusisto said:

> I wanted to start this consulting organization called "Now That's Fucked Up." You'd come into a place that was only working marginally, and we'd really fuck it up. And then they'd be so grateful for how things worked before we got there . . . and that would be our slogan, "Now, that's fucked up." (p. 152)

Crude, but it really sums up the disability experience for many people, and certainly expresses our frustration with the CDSA and public schooling — so many people telling us what to do, how to do it, and how much our broken lives needed fixing, and eventually it gets to the point you realize you were better off without the interventions. We left sabotage therapy and asked the therapist never to return to our home, and I think I told her where she could shove that big red button.

Conflicts with service providers leave deep wounds that take a long time to heal. You have to have a sense of humor to survive. And you have to know when to leave a relationship that has become detrimental to your or your family's health. For Kenyon, therapy had become a hazard and perhaps even harmful. For Kenyon, public school was transforming him much faster than it did Liam. A red buzzer pushed us over the edge, not in and of itself, but of what it represented; years of endless therapies involving forcefully

strapping him into chairs, repetitive rote exercises, and meaningless quantitative measures about stacking blocks or poking fingers in PlayDough, and meeting after meeting with case workers, STs, OTs, and PTs whose only goal was to fix him and fit him into a box called *normal*. An EOG prep worksheet about temperatures pushed us over the edge about what public school was doing to Liam, but it wouldn't be the confirmation we needed to push us out. That came next.

The Incident

Kenyon stood there
wondering
what just happened
to him, one minute
he was dancing
to *The Wiggles* CD blaring
from the cheap
speakers on his teacher's
computer
and the next
minute he's stuck
standing there
exposed
his pants at his ankles
his wet pull-up peeking
out of his
crumpled up jeans
his uncircumcised
penis
showing
and now all his classmates
staring, laughing, giggling
God-Dammit I can't speak
but I can hear
just fine
he says inside his head
but it comes out *no*
no, no, no, no, no
his teacher chides
Kenyon!
oh my god
what have you done
this time
she struggles

to figure out
what to do
but manages
to yell
at the class
BE QUIET!
Kenyon thinks she's yelling at him
he starts to cry
she gets his pants up
muttering something
about the last
straw
she pulls him
by his little hands
to a bean bag
shoving
his favorite *Backyardigans* book
into his lap
but he wants to dance
that's all he ever wanted to do — to dance.

Janet called me as soon as she heard. Kenyon's teacher, in a seemingly unending quest to find reasons to remove Kenyon from the classroom, had another *incident* to report. She reported that Kenyon has exposed himself three times in class today dropping his pants and pull-up to the floor and standing there for all to see. What? No. Not Kenyon. He had never done anything like this before. If anything, he was modest. Something else was going on here.

But for now, the judge and jury of teacher and principal had settled the case — that Kenyon was guilty of exposing himself to others. Janet ran to the classroom and took Kenyon out. She took him to the bathroom to go potty. When she did, she noticed the buttons on the elastic loops inside his pants were undone. This was great news. It wasn't Kenyon, it was his pants. Janet explained to the teacher who looked doubtful. She simply repeated the story that he exposed himself and it wasn't appropriate, and we were going to have to do something about it. Janet explained Kenyon had new pants.

Every parent knows kids' pants come with an elastic band on the inside that you button shorter or longer to adjust as the child grows. The buttons on these new pants had come undone — not uncommon, it's tough to button those little buttons until the pants get broken in good. But why didn't the teacher know this? Shouldn't something as basic as how children's pants work be something a kindergarten teacher knows? Why didn't she investigate? Why didn't she figure out what any parent would have? Why did she let this happen to Kenyon three times? Why?

Yes, this young teacher had no experience as a parent or with children other than in the few years she taught, so perhaps we shouldn't expect her to know, but shouldn't it be something taught? Yes, she was super busy, too busy. The system didn't hire substitutes when the classroom assistant is out sick, so the teacher was all alone with 20 kids. The teacher had told us several times she wasn't comfortable touching children, so no wonder she didn't investigate. It was probably all she could do to get herself to pull his pants back up. But how in the world did she get hired as a kindergarten teacher, and moreover, how did she graduate from a school of education thinking she could be a teacher without physical contact with children? But the incident was symbolic of much larger philosophical issues.

She and most other people at school never presumed competence with Kenyon. Fault or solution can't be found within the system, it must be the fault of the child. So, presuming blame was always the first option. Kenyon's pants are down — he must have of done it. A peer says Kenyon took a toy — Kenyon must have done it. Kenyon's crying — it must be his fault. Kenyon's not performing on this assessment — must be

something wrong with him. Always deficit-thinking caused the first assumption to be — he can't, he didn't, he won't, he did it on purpose, it's his fault.

Our meeting with the school's pre-referral team was later this week. This incident would put it over the top and we'd have no hope of trailblazing a new path. This story would force us down a road we didn't want to take. The pants incident put us over the cliff. Now not only did we feel the school didn't want Kenyon there, but that they didn't care about his well-being. Even if we entered the special education system, would things be any different? Having an assistant there with him, which was a huge leap to assume he would qualify for, would only mark him further and further segregate him inside a classroom that would be labeled inclusive, though in truth would be a practice of exclusion. Right now, Kenyon was fully included in all classes all day long — but Kenyon was alone. We couldn't find the right side of the inclusion/exclusion binary. What we needed was a third way.

> **GLIMPSE, December 2010:** Snow, snow, snow. We have so much snow that school is only held two days between Thanksgiving and the new year. The boys are home, healthy, and — without the influence of public school culture — returning to the people we once knew. Liam is reading for fun, playing music, and drawing. Kenyon is healthy and happy and engaged. We play, we travel, we sing, we dance, we explore, we learn. Life is good. We dread the start of school. Why go back?

> **GLIMPSE, Fall 2012:** It's frigid. In the low 20s. There is snow on the ground. But it is time. I've put it off far too long. It seems like such a short time ago that I ordered all these pro-inclusion bumper stickers and put them all over our cars. The cold weather makes the bumper stickers brittle and easier to scrape off. Inclusion is NOT just education.

A Homeschooling into Unschooling Story

> **GLIMPSE, December 29, 2010:** A month at home with our two boys taught us that we love learning together. It gave us the distance to ask critical questions about the schooling taking place at their elementary school. Neither boy was thriving in public education. We had enough privilege and capital to homeschool. So we began our new journey. We deschool.

Thanks be to Snow

The snows cancelled our meeting with the school-based assistance team. First one day of school canceled. Then two. Then a week. The snows kept coming. The ugliness of the bitter world was covered in a blanket of pure white. Between Thanksgiving and the holiday break, school was only able to be held two days because of the snows. We kept the kids home both of those days. Over the course of more than a month home with the children, we began to realize how happy we were. How Liam was re-emerging as the loving, kind, and thoughtful boy he has always been.

Kenyon's allergies were gone. The doctor had told us it might be the dust and mold at school, but now it was clear. We took him off his medications and he did fine. No allergies at all. Kenyon was also returning to his typical self. He flourished at home. Both boys did. They read, played games, played outside, we explored, we took field trips, we built forts, we played music, we danced, we traveled, we visited relatives and neighbors, we volunteered, we did crafts, we sewed, we did puzzles, we told funny jokes, we talked, we bonded, we re-connected as a family in a way that left us realizing what had come between us all — public schooling. Not only in the attitudes, social behaviors, and negativity produced by being in public school, but by the onslaught of homework,

EOG test-prep packets, and endless battles over getting homework done. With the amount of homework assigned there was hardly time for family. Reading had become something logged on a sheet. Liam would only do the 20 minutes a day of required reading. Before those log sheets he read for hours every day. Now, in this snowy December he was reading joyously again. Instead of being limited to Accelerated Reader lists for which he was quizzed via computer, he picked his own books to read. We visited the town and university library and he came back with a treasure trove of books he would never have been allowed to read in school.

We were free. We were happy. We realized this is the life we wanted. We wanted to live a life learning together. It was an epiphany. Sitting in the kitchen over-joyed with the lives we were living we began to get depressed thinking about the fights ahead when school resumed. Why go back? We had the privilege of education and money that allowed us to homeschool. Why not? So, we filed the paperwork and vowed not to return. And it has made all the difference. Thanks be to snow.

> **GLIMPSE, Spring 2011:** It's the end of our first few months of homeschooling. I'm in a Ph.D. program. I'm teaching at Appalachian State. Life is good. I've been juggling family, school, and work for years. Of course now I'm homeschooling the kids, too. Time is at a premium. We're figuring out what to do. If it feels like school, we do something else. We seem busier than ever, but in a good way. Kenyon loves the Wii, computer, and watching his favorite television shows. His growth in manipulation of the Wii controller is amazing to watch. Liam is upstairs in his room a lot playing music. I love hearing the music above my head as he plays and I cook, clean, study, and prepare to teach my night classes.

The Mask I Wear

I sleep deeply, but every morning like clockwork at 8 a.m. the bedroom door squeaks open. Just a crack. Just enough for the dull, yellow light from the cheap compact-fluorescent in the hallway to make me squint. The little eyes of my youngest child peep through the crack. I think he listens for my labored breathing. I sound and look like a translucent Darth Vader sleeping on my back, my full-face apnea mask and accompanying hose jutting into the air rising and falling in sync with my heaving chest — choooo-kssssh, choooo-kssssh, choooo-ksssh….

Kenyon slides through the door, closes it, and crawls in bed. Sometimes he goes back to sleep. Sometimes he knocks on my mask. Sometimes he leans over and presses his face to my mask and stares. I wonder what he sees through my mask?

Inevitably, I pop the two side-clamps, untangle the hose, and pull the mask off setting it on top of the breathing machine beside the bed. Kenyon and I meet nose to nose, foreheads together, he strokes my beard, and places a finger in the hairy dimple beneath my nose. I squeeze his earlobes, rub his back, and pull his little legs under the covers to warm his feet. I kiss his cheeks, we stare into each other's eyes, we hug, we converse through flesh pressed warmly together in a morning welcome. I think this is as much a greeting of relief as it is of welcome. I think he is glad I survived the night. My doctor tells me people die of sleep apnea. Before my diagnosis, I thought I would die. I couldn't stay asleep or awake more than two hours at a time. I hallucinated. I couldn't concentrate. I was constantly tired. My condition rapidly deteriorates once I hit a tipping point of a few days with no REM sleep. When I don't get my breathing treatments, I fall back into extreme tiredness and lose concentration, but it is more an impairment than disability and is easily managed, if I commit to sleeping eight hours with the machine.

I'm glad Kenyon survived the night, too. A shunt keeps him alive. I rub it every morning just as he rubs my mask. I trace the path of the shunt tubing from Kenyon's head down behind his ear, along his back and around to his belly. It took five hours of surgery to install it. He was five weeks old and weighed about five pounds. His neurosurgeon tells me people die when shunts fail. We live two hours from the nearest pediatric hospital. That's just enough time to get there.

Once we realize the other is alive, we begin our day and continue our corporeal conversations of the flesh. Kenyon speaks one word — "no." But it has many meanings. It can mean literally "no," or it can mean "yes" or it can mean "maybe" or it can mean "perhaps" or it can mean "I'm thinking" or it can mean "wait" — in deciphering what "no" means, you have to consider the context of the

conversation. It helps to know the history, too, of what Kenyon has meant by "no" and its various inflected and punctuated forms.

Kenyon has an ever-evolving vocabulary of signs (including ones he's created) and he reads a bit and understands a great deal of connotation as well as denotative meanings of words and phrases. The vast majority of Kenyon's communication is nonverbal through touch. It's a language others can learn, but no one speaks it as well as Dada, Mama, and Brother. We are all so comfortable touching each other, it seems strange to enter all the other social situations in our lives where touch is a rare form of communication.

Sure, we might shake hands or give a hug, but how rare is it that we humans touch each other as a form of communication? I certainly don't touch at work. I teach. I'd be run out of town on a rail for touching another person. How sad. I use words at work. My office is filled with books, stacks of PDFs, and my classes focus on oral and written communication. My world at work is the spoken and especially the written word. The academy privileges the written word so much that our primary vehicles for hiring, promotion, and honors are the publishing of our words as research.

I'm going to spend my life working in words. But what about Kenyon? He will never be able to access my words. Hell, with the jargon and forms we write in in the academy, a lot of folks won't be able to access my words. Shouldn't we explore ways to make research accessible to all people, including Kenyon? Can I create research that both counts as research in the academy, and is in some way understandable by Kenyon? Could I rely less on words and more on the visual representation/performance of my research in photographs and video? Isn't this an issue of power? Words exclude. Isn't this a way to maintain the status quo?

Unschooled Life

In many ways, an unschooled life looked a lot like any other life. As a family, we still had to have the difficult conversations of life that most families, at least I think most families, eventually have to face these issues together in some meaningful way — conversations about money, loss, love, sex, drugs, alcohol, smoking, politics, fire, war, poverty, oppression, harassment, violence, human rights, civil rights, gay rights, voting,

just to name a few. For us, these conversations were many times car conversations because we spent a lot of time driving as we traveled.

As unschoolers we had a need to shop, just like other families. But perhaps, because we were at home so much, we felt a need to buy more. Luckily, our community had a strong thrifting, resale, and donation vibe with two Goodwill stores, a dozen consignment stores, and several annual toy/clothes sales by local churches that resulted in a treasure trove of shopping sprees for very little money. In one way, the availability of cheap used toys and games, perhaps put too much of an emphasis on things over activities. But when you can buy any used board game for $1 at a local thrift store, or a paper grocery bag full of books for $1 at the annual library book sale, or find deals like a gallon Ziplock bag of Hot Wheels cars for $1, it not only gives you chance to have dialogue about the economics of thrift and environmentally friendly choices of reuse, but you get to have a lot of fun with all the stuff when you get home. Our home became chockfull of cars, action figures, games, books, Legos, building blocks, building sets, puzzles, and sports equipment.

Kenyon loved dolls but was very particular about which ones. We often bought these new, because he rarely found a used doll he liked. He would love on the dolls, play doctor with the dolls, and make the dolls enter elaborate dance competitions he would act out as emcee.

As unschoolers, like other families, we went to the movies, but since we could go during the school day, we often had the theater to ourselves and our tickets were cheaper, too. Visiting the places other families visited, but at non-peak hours not only saved us

money, it gave us the run of the place most of the time, besides other homeschoolers and sometimes school groups. We frequented libraries, children's museums, public pools, parks, museums, science centers, county fairs, amusement parks, ski slopes, hiking trails, greenways, parkways, lakes, campgrounds, and many times we reveled in both the attention from park rangers, librarians, etc. we received, and the free roam we were allowed because we were often among the few people there during weekdays.

As unschoolers, like other families, we had the daily grind of chores like cooking, washing clothes, cleaning, yard work, and the seemingly endless tasks of everyday living from paying bills to taking the car for repairs to checking the post office box. Sometimes, I struggled to understand how other families got everything done. We seemed to never have enough time to do it all. We were always on the go. Sometimes hurried. We didn't feel all that different from other typical families.

As unschoolers, like other families, kids came over to play or we met them in town. Because of a large homeschooling community in the area around our hometown, there were always kids out during the school day at parks and libraries and creeks and lakes, or wherever we found ourselves. Because we were also in a tourist town, there were often kids on vacation to meet. Beyond kids there were people everywhere we went, and our kids interacted with all of them.

As unschoolers, like other families, we did many of the traditional *after-school* activities kids do to explore and find their personal interests from music lessons to art camps to baseball to swimming to soccer. Kenyon participated in a baseball league for kids experiencing disability for a few years, but while he enjoyed the social aspect, he

didn't seem to enjoy the hot sun, sweat, and dirt of playing baseball in the summer, so we let that go.

But we did less typical activities too, such as horseback lessons and theater. Kenyon loved being on horses, but his hip dysplasia eventually made being in the saddle too painful. Liam did several productions of community theater and landed the lead one summer for a show. He especially enjoyed an annual Halloween variety show done by the local community theater that was broadcast on local radio. Liam had a knack for memorizing lines of dialogue, which made him a natural for theater. Liam followed some homeschoolers to an audition for our local outdoor drama Horn in the West. He ended up being in nearly 150 shows over the next three seasons, including a lead role as co-narrator his last season. I believe his early theater experiences laid the groundwork for his music career. Instruction in voice projection, body language, and stage presence all translated well to the music stage. Time in front of large audiences gave him a comfort level not only onstage, but in interacting with the public. Horn in the West, in particular, depended on its cast members to hit the streets of Boone before shows handing out fliers in costume, talking up the night's show. They also hit the local radio shows, TV shows, and did interviews with the press, and Liam was often involved, so he learned many of the skills a public performer needs and got to practice those skills early.

Like many parents, we volunteered and became involved with whatever activity our children were involved with at the time. So, we didn't often just dump the kids off at the front door of an activity, we were there helping. In some cases, as in the theater, it was more of a dump your kid at the door and come back. In other cases, like sports,

teams needed help coaching. In the case of Horn in the West, it needed all the help it could get. Since I was dropping Liam off six nights a week, I became involved volunteering for public relations and promotions, and eventually became a board member. This too, working together, was good training for what was to come next in music. Liam has the musical ability to lead a band, but I had the management and public relations skills to do work to book, promote, and manage. We made a good team. It wasn't always easy, but we had watched conflicts on his sports teams over the years between parent coach and child, so we were able to avoid some pitfalls through talking it through. We had also learned at Horn in the West to give each other space — front of the house and back of the house, as they call it in theater.

When the music started taking off was really when our lives started to diverge from the experience of other families, whether public schooled, homeschooled, or unschooled. It was gradual, but our weekends and summers became focused on playing music, which meant travel. We bought a used RV, then bought a bigger one. Some people might say we quit unschooling and started road schooling. But we never saw it that way. In fact, I rarely thought about the fact we were unschooling. To us, we were just living. There was no difference in schooling and life.

> **GLIMPSE, October 2011:** I get out of class late. It's dark outside. The professor always goes 20 minutes over, but no one cares. I love this class. But today my family is waiting in the lobby. They made the two-hour trip from Boone to Greensboro with me. It's tough commuting to graduate school and it's nice to take the family along once or twice a semester. Janet wanted to visit family while I was in class. Janet, Liam, and Kenyon are all in the lobby and so is an old friend, Sam [name changed]. Sam experiences Down syndrome.

He goes to college here in a special program that makes it possible for students with development disabilities to attend college, but I've known him for many years outside of the university. He is from the same town as Janet. Sam has been crying. "Hey buddy, what's going on," I ask him. He recognizes me, hugs me, and says, "I don't have anyone to walk home with me." I call Liam and Kenyon over. I wonder if he knows Kenyon has Down syndrome? Liam talks with him. Kenyon shakes Sam's hand. Janet pulls me to the corner and tells me he's been there for more than an hour trying to get someone on the cell phone and crying.

"Sam, we can can walk home with you," I tell him. He agrees. Janet takes Kenyon and follows us in a car. Liam and I walk seven blocks with Sam until he is safely inside his apartment. On the drive home, Janet and I debate. How we would feel if that were Kenyon? Is college a safe space for students experiencing developmental disability?

Wild Pitch

The first year of kid-pitch baseball is tough. Up to that point the coaches pitched the ball or a machine. But kid-pitch meant wild pitches and one of the toughest things to learn was to get out of the way.

"Hand hurt?" I asked.

"Yeah," Liam said.

"Need more ice?" I asked.

"No," he sighed.

Liam loved baseball. The coach always put him at third base. The most skilled players filled the bases from the catcher at home plate to first and second bases, and short stop and of course the pitcher. Third base was just short of being in the outfield where typically the less skilled players played. Liam didn't have the skills of some of the other kids, but the coach said Liam was one of the only players who understood the game as a thinking game. Third base was the furthest from the coach's box and dugout, so you were

on your own a lot. We liked Liam's coach. He had coached him for years. He was always understanding when Liam had a choice to make between music and baseball. As you moved up through the leagues the games became more frequent and now Liam had to make tough choices between attending a music festival or being there for his team. Liam struggled with the choice between his team and his desire to go play music.

A wild pitch hit Liam across the knuckles crushing them between the fastball and metal bat. It scared me, but it really scared Liam who experienced the pain. No broken bones. Ice, ibuprofen, and time took care of it. But the coach told me the next game…

> Liam's not going to be a professional baseball player, coach said. I love him and don't want to lose him from the team, but he will be sitting on the bench in the next league. It gets tougher and tougher and rougher and rougher. You not only have wild pitches, but benches clear and kids fight. A lot of injuries happen sliding into bases. It's not a good sport for fingers.

He spat on the ground and rubbed it in with his cleat.

"What are you trying to tell me, coach?" I asked.

"Don't let him make the wrong choice, that's all. And send me a CD when it comes out, ok?"

Coach was right. Liam decided on his own. He never quite recovered from the wild pitch. He finished the season, but hung up his baseball hat.

Tinker

I pulled weeds. Liam watered. I loved gardening. It was something we did together all summer. Liam especially loved going out each day to see what seemingly grew overnight. Lifting up the broad green leaves to see if any cucumbers were ready to

pick. Peeking under the straw for strawberries ready to eat. Pulling apart the brown tassels on the ears of corn to see if the tender kernels inside might be ready to go boil.

I expanded the garden each year. Liam was taller and stronger each year and could help more and more. My aunt and uncle called one winter to offer my grandfather's old tractor to me. I took it. When I was a child I rode that tractor all the time and when old enough, drove that tractor for hours upon hours in my youth helping my grandparents tend our garden. I plowed up a quarter of my yard with that tractor, so we could keep on growing more and more. Liam found a white, quartz arrowhead in the newly furrowed rows.

"Dad," Liam said. "Don't you think this is too much garden? How are you going to have time to clean out the buildings like mama told you to?"

It was true. There were two buildings near the garden that were *mine*. Chockfull of tools, wood, boxes, gear for camping and fishing, and just plain junk. Liam asked, "why don't you just set the buildings on fire to clean them?"

He was joking. But he had a point.

"Well, I like to tinker," I said…

GLIMPSES, 1979: My grandfather stepped out of the dark shadows of his cinderblock workshop carrying a small, black caldron. He cupped his thick, callused hands around the iron forming an outer bowl of flesh, holding it sacredly, as if performing some ancient ritual. I was nine and felt like an apprentice to some modern version of a medieval magician. Only instead of a robe with stars and moons, my 70-year-old grandfather wore dirty coveralls spotted with paint, tar, and soot, and in lieu of a wand or staff, or star-on-a-stick, he wielded a pocket-protector chock-full of pens, pencils, miniature screwdrivers, and a magnifying glass. He had the wizardly white-hair on head, eyebrows, and arms, and to me he worked wonders within the space of his garage, which rarely housed a car, but

instead was full of tools, metals, wires, and stacks upon stacks of Tampa Nugget Cigar boxes overflowing with transistors, resistors, and capacitors. He was a TV repairman, sort of…radios, too…as television sets got cheaper, there seemed to be fewer and fewer customers, but that was ok because it gave him much more of something that mattered most — not money, but time.

He liked to tinker and explore and shift and move from task to task and from job to job. I really don't know of any permanent job he held outside of something he could do from home or out of the back of his '62 Ford pick-up. He was a beekeeper, a gardener, a mechanic, and a mason. He was no jack of all trades and master of none. He was a skilled mason, who could build a chimney or a house foundation, and he did both not only on his own house, but on many homes in our extended family. He kept bees and knew how to get good honey. He grew grapes and made his own wine in an old glass-jar press. Around his garage were stacks of brick, stone, other leftovers from building projects. Inside was a maze of old TVs, tubes, and speakers. Shelves lined each wall overstuffed with fishing rods, tackle boxes, glass jars full of sundry nails, washers, nuts, bolts, and coffee tins each one dedicated to holding sets of alike tools. Screwdrivers were in the red Folger's can, pliers in the blue Taster's Choice. His garden covered about a half-acre and he plowed it with a 1946 Farmall McCormick Cub.

This night was about making. With furrowed brow, bending down on one knee, to where I lounged in a makeshift chair I fashioned out of a couple of old tires, he gave me the caldron and said, "feel this, you can't touch it again until after we finish making." He called everything making from getting up wood for the winter to stringing up hogs for slaughter to turning dirt for planting. We seemed to make everything during the many childhood years I spent living with my grandparents.

This November night in 1979 resembled most nights in our little country holler by the creek, when after a full day of making we still found ourselves working as the smeared colors of day, dusk and night blurred beyond the pines, and the mercury lights clicked and began buzzing to life. Grandpa disappeared back into the building through the open garage door. I could see the glowing pumpkin-like teeth on the grill of the pot-bellied stove inside. The cold and heavy caldron looked larger in my little hands. Grandpa returned, setting up a steel tripod with a chain hanging from the triangulated peak. I hung the bowl at the chain's end and we both began to build a fire underneath from scraps of wood gathered inside the workshop, twigs along the creek bank, and pine limbs left in the yard from a recent storm. The contraption looked and worked like a miniature version of the giant kettle we used a few weeks earlier to cook beets for canning and to brew up Brunswick stew.

These cold fall days we worked packing the dirt cellar with Mason jars of beans, tomatoes, and beets. It was a time for gathering all we would need to make it through the winter. We packed the chest freezer with corn, okra, and beans. We packed the upright freezer with paper-wrapped beef, steak, and sausage from the cow and pigs slaughtered in September.

Kids Ask the Damnedest Things

Liam asks. I answer. I ask. Liam answers. If I had to explain our usual unschool method of learning it would be as simple as that.

"Why do we have to stack this wood?" Liam asks.

"So it doesn't rot," I answer.

"Who cares if it rots?" he asks.

"You will when you need it," I say. "Who knows when we'll need these. But these timbers will last for years if we just get them off the ground. You keep wood off the ground, a little air underneath, and it will last."

"What's next?" Liam asks.

"We could try fixing the four-wheeler," I say, but he doesn't look excited at the prospect of tearing apart the engine again. "Or I need to caulk the upstairs window again, you can go up on the roof with me."

Still, he looks uninterested.

"I've got a long list," I say. "We can sharpen the blades on the mower, need to check the mouse traps under the house, need to go down and straighten the mailbox again, some drunk must of hit it, your mother wants us to carry that stack of boxes to the attic, or I know, you probably wouldn't want to, but we could go fishing…"

Smiles.

"I'll get the poles," he said.

Sitting on the bank by the lake Liam asks, "What's wrong with Grandma?"

I cast. "Why?"

Liam looks at me with what one of his uncles calls his 40-pound eyes, and says, "I heard you talking to the police last night."

GLIMPSES, 1977-1982: Bill Miles ran a greasy corner store at the intersection of Lake Brandt Road and Highway 150, just a short mile and a quarter walk for my brother and me. I asked him for a job. If we picked every downed limb out of his oak-tree-filled yard, he said we could have any two things in his store. It took us two afternoons from the time we got off the elementary school bus until dark to finish.

Mr. Miles led us to the candy stand and smiled. I walked away from the candy shelf and over to the freezer and took out the largest pack of bologna and a gallon of milk. Mr. Miles looked confused. He had said any two things in the store. My brother and I had been eating mayonnaise sandwiches all week while my mother was on another drinking binge.

The divorce court judge gave custody of us two boys to my mother. It didn't last for long. Mom worked second shift at Maid-Rite Foods slapping pimento cheese between triangle-shaped bread, sandwich after sandwich, hour after hour through the night. I raised my brother. I cooked frozen Salisbury steaks and canned biscuits. I sliced thin the blocks of government cheese. I split wood and kept the stove fired.

Sometimes Mom would forget to leave money for things at school. I learned to steal from her, squirreling away change to pay for fees, pencils, field trips and occasional ice cream treats. I learned to forge her name, treat a cold, write a check, fix a toilet, and to mask my fear because I was my brother's keeper.
For a short while, we moved to Charlotte, where I was only white kid in the third grade. My bike was stolen. Our car got stripped and put up on blocks. I learned to take a beating and I learned to fight back. Fun at the apartment complex meant jumping on old mattresses in the woods, playing pinball, crawling through drainpipes, or finding things to toss over the fence into the gangrene-green pool. The News 3 helicopter landed at our school for Christmas on a baseball field full

> of hundreds of black children cheering, and me, too. I stood in shock to see black Santa step out, but I took the candy cane. I learned about black Jesus, too. Race didn't seem to matter too much to us kids because we all had poor in common. We stayed at home alone a lot while my mom worked second shift. Alone one night, I held my little brother tight and watched the silhouette of a man take off the screen to our bedroom window. The dog woke up and jumped at the window, and the man ran away. The decision had been made weeks earlier for my brother to go live with my father starting the next month. I didn't look forward to nights alone. My Aunt Elaine and Uncle David offered to take me into their home and raise me.
>
> I was twelve. I didn't have much to pack. Some clothes, a Nerf football, a bike. People who knew me then and know me now ask me how I turned out the way I did. I should have been trailer trash locked up in jail or Butner Mental Hospital like my mom. Maybe should of had three kids by three different mothers, living life from 12-pack to 40 ounce, smoking Winstons, eating pork skins and Little Debbies, cheering Dale Jr. while fighting with my neighbors over my chained-up pit bull that barks all night and leaves redneck crop circles in the overgrown crabgrass outside my single-wide. (Purcell, 2008, pp. 94-96)

Raking Coals from the Fire

When my mother couldn't take care of me, and eventually, when I was taken away from her, I spent my time between aunts and uncles, but much of it with my paternal grandparents. A neighbor up the road built and raced soap box derby cars, and invited me to join. Even if we could have afforded it, you can't just buy weights to fit in derby cars. Just like the cars have to be handmade, you have to make the weights. Grandpa didn't pretend to understand why I wanted to build or race a derby car, nor did he ever attend one of my races, but that wasn't any different than how he treated his own kids growing up or any of his other grandchildren. He nor my grandmother, nor my parents really were the types to attend school plays or concerts. School was a place you sent the kids, it wasn't a place to go. And I never thought much about it. I got plenty of

time with him during chores, fishing, and on nights like this where though he pretended not to be interested, he seemed secretly proud to be able to help.

We filled the caldron to the brim with an assortment of nuts, bolts, wires, nails, and any metal scrap we found. As we waited for the fire to melt the metal, uncles and aunts showed up, as they usually did. The entire extended family lived within a 10-minute radius of each other. Soon a crowd of men gathered around the fire. I listened and observed, taking note not only of the stories told, but how those stories were told, and who spoke when, and how much. The Purcell and Pulley men and women could weave stories together much as they fashioned food, music, and fun, out of whatever means they found in the world.

My dad's side of the family, all of Irish and English descent, were and are still working-class folks, blue-collar folk, who scraped to make do. Some found regular work in the textile mills, but others used a variety of skill sets from sewing to masonry to carpentry to gardening all to cobble together an existence that eluded a strict 40-hour work week. Our family relied on relationships and everyone came together to build houses or garages, to get up tobacco, to make quilts, or to fix cars. These relationships meant sharing not only in the work, but in the fruits of the labor, so the family split potatoes grown at one house into bushel baskets to share, pecans gathered at another house into buckets to share, and objects from clothes to cars to furniture traded hands from family to family as needed.

A stranger might look upon the line of scrap cars, assorted piles of wood, brick, or tires, the makeshift buildings cobbled out of tin and wood, or at the mismatched furniture

and tableware as some sign of poverty or hoarding, or both. But my grandparents saw the value in things that other people didn't see. And it was the same way with how they saw people. A teacher or preacher or politician might write a Purcell kid off as a scrap heap of unfocused, unkept, uncouth, impoverished, trash biding time on society's dime until it was time to go work in the mill. But for me, what mattered was what my grandfather saw, and what my grandmother saw — good raw material with potential.

Smoking Tampa Nuggets

Grandma was a lot like Grandpa — a tinker in her own right. Her medium was fabric and food. Whether Sunday dinner or a quilt, she could weave together a masterpiece out of whatever was at hand. Dorothy was short and round with white short curly hair. Her polyester dress whirled as she directed a kitchen full of my aunts, my older girl cousins, and a few babies crawling underfoot. The crew cooked up tender roast beef or chewy chuck steak or bread-battered pork chops, buttery mashed potatoes, greasy collard greens, cucumbers soaking in a bowl of vinegar, fried cornbread, crowder peas with chunky fatback, fried fatback, tender green beans mixed with new potatoes, butter beans or limas or blue lakes or snaps in a bowl, macaroni and cheese from a box, pickled beets and squash and peppers, mustard slaw, fried squash with onions, thick sweet tea, the softest biscuits in the South, and lemon pie with a Nilla wafer crust.

They were both improvisors, creative, artists, and skilled craftspeople, with a strength and purpose to their work, whether to keep someone warm, keep them fed, or to lay a firm foundation on which to build. I lived with my grandparents on and off throughout my childhood. We didn't have much money for toys. But the endless tools at

hand from my grandfather's workshop or my grandmother's attic provided plenty of self-made entertainment. I'd gather leftover bricks, empty thread spools, pine cones, and scrap wood to build castles in the gravel drive or along the sandy spots in the creek. Using the thick, green, oblong seed pods of the Catawba tree I'd put the tip in my mouth and pretend I was Grandpa smoking a Tampa Nugget cigar.

> **GLIMPSE, around 1978:** I learned to hate spelling from my father. Sometime around the third grade he started to try helping me with homework. He was still around then. This was before the divorce. I don't remember if I had trouble or he just decided to take an interest. Either way, I wasn't doing too well. It was the first time I began to fear spelling. He checked my spelling worksheets, quizzed me, told me all I got wrong, and sent me back upstairs to work again. I resisted. I defied. He punished me.
>
> I loved model cars. He worked as a cashier at a Seven-Eleven. This store had everything — including model cars. He would bring me home one every now and then. Those models were the first things to go. He gave up on spelling after a few weeks of me failing over and over. But I did learn something — to hate spelling.

> **GLIMPSE, around 2011:** When teaching or guest lecturing, I always get to class early so that I can write on the board before anyone gets there. I write all the words I'm going to use before the students arrive. I do this so I can use a dictionary application on my iPhone to double-check my spelling. Even now as a 40-something Ph.D. candidate, I struggle with spelling.
>
> I've hidden it, worked around it, and learned to cope with it. It's the same way with my lisp, which started after a botched wisdom-tooth removal that left me with no feeling in the left side of my tongue. It only comes out when I'm nervous or extremely at ease, when I don't care how I sound. People don't judge my lisp, it's so slight. But an academic who can't spell?
>
> The irony is that all my life I've made a living with words. Yet, I fear words. During class I underline, circle, or connect what I've already written out as I lecture. It's pretty effective technique because students see an unconnected set of random words on the board that by the end are connected through lines and boxes and colors.

One of my professors asked me to teach disability theory to a graduate class. Of course I said "yes." This was my first chance to guest lecture in a class of Ph.D. and Ed.D. students. Wow! Class went great. I did an hour and half and could have gone longer. At the end my professor asked me to write some concepts on the board as she spoke about them.

The first word — "hierarchy." Even now, it took me a couple of minutes to figure out how to spell hierarchy using a keyboard and spellcheck. That tells you how far off my first attempt at spelling is. I'm standing at the board, frozen, a dozen graduate students staring, my professor waiting — I can't spell it. I have the "h", but don't know what comes next.

It seemed I stood there unmoving for an hour, but I know it was under a minute. I thought, "I don't belong…I can't do this…I'm white trash…I can't escape my roots…I'm ashamed…who am I…what am I doing in graduate school…I don't deserve to be here…I suck…I'm so embarrassed…I can't turn to face the room…what do I do?" Silence. She said it again as if I didn't hear it, "just write hierarchy up there." I stood frozen.

She looked up and met my eyes. She turned to the class and said, "everyone struggles." She turned to me, "William, you struggle with spelling don't you?" I said, "yes, I'm sorry, I always have. It's my Achilles' heel." She said, "it's ok. It's a good example that we can overcome our struggles. H, I, E, R, A, R, C, H, Y." I said, "thank you." I kept writing and she and others in class helped when I needed it. Everyone struggles.

A Letter to My Classmate

An excerpt from a letter I wrote to a classmate in one of my cultural studies graduate classes after we argued in the hall and in the parking lot after class about a criticism she made of me in class, saying I "over-romanticized" disability and that perhaps identifying disabilities prenatally, so that abortion becomes an option is the better solution.

Dear A.

I wonder if missionaries cautioned Native Americans not to over-romanticize their tribal culture or if the Protestants cautioned the Irish not to over-romanticize their Catholic culture.

It is very easy for someone outside of a self-defined culture to define that culture or its validity for them. I would caution doing that with disability culture. Devaluing, denying the validity of, or accusing that culture of over-romanticizing itself is a first step of deculturalization.

I think what you are talking about is not disability, but illness. There is a huge difference. Yes, everyone should be concerned about preventing an illness or stopping a disease. It is one thing to perform a surgery on a spine in utero or to perform heart surgery to close a hole caused by a genetic difference on a chromosome --- those are illness issues. It is another thing however to prevent that life from being born because they might move, breathe, or communicate differently.

Often people try to link disability with suffering. However, I believe the majority of people experiencing disability do not suffer from their disability, they only suffer from the prejudices, injustice, absence of access, lack of opportunity that society uses to continue to deculturalize disability culture.

No one suffers from disability, just as no one suffered from being Native American or Irish, however they suffered mightily from the society that saw their culture as one that needs to be fixed, that needs to be changed to a state of "normal." Just as the missionaries tried to fix the Chickasaws into their version of normal, so do many doctors, nurses and service providers try to force people experiencing disability into a their own version of "normal." Now if that person experiencing a disability has a fever, a growing ventricle, a tumor, etc., then yes, let's address that disease or illness, that is what doctors and nurses are for. If therapy will help with walking or talking, then great! Let's do some therapy.

But if for the first 12 years of your life you spend multiple hours a week with therapists asking you to squeeze a ball, put your finger in play-dough, put their finger in your mouth, strapping you in a chair so you won't crawl away as they flash cards in front of your face, years and years of people sending you the message that you do not fit into normal and we're going to try everything we can to force you into this mold of normal - that is deculturalization. That is robbing someone of their identify. Disability is natural. Disability is a natural part of the human experience. Having a disability is ok.

> Let's not give in to the medical model of disability that says everyone must be fixed to someone else's standard of normal. Every culture has a right to define itself, and every member of that culture has a right to self-identify or not with that culture...when we take those rights away, we start deculturalization.
>
> I would add that we should also move our language to put people first. We should always say and write "a child with a disability" rather than a disabled child, or a baby with spina bifida rather than spina bifida babies. People are people first and their particular disability is one part of their lives and not necessarily the most defining part. You hear so many times, that student is cerebral palsy, or that kid is Down syndrome. No, his name is Kenyon, he loves basketball, playing computer games, laughing, eating ice cream, he gets very angry sometimes, he loves people and oh, he also experiences disability as Down syndrome.
>
> However, all that said, I really respect your right to believe the exact opposite or to see it differently, and I really value you and what you do for your students and their families, and most of the time I don't really care too much about offending anyone in my advocacy efforts, but I do care about you and what you think, and I thank you for always challenging me and my thought process, and I hope you'll still sit beside me even after you read this letter.
>
> Best, William

Hearing No

April 19, 2012

Liam received an envelope in the mail, he saw the return address and jumped for joy yelling "I got the scholarship, I got the scholarship." He never applied for anything like this before, he didn't know they also sent rejection letters. This was a competitive bluegrass scholarship to fund lessons. He worked hard writing an essay, filling out the paperwork, recording a CD of his music. What made the rejection letter worse was his confusion. He really thought getting a letter meant winning it.

He opened it. He read he didn't get it. That is one of those many sad moments for a parent seeing the face of a child go from joy to sadness. Parents know that pit in our

stomach as we feel what our child feels. I know it's a great life lesson, and that like me, like all of us, this is one of hundreds of rejections he/we will deal with in life and it is good to learn early how to deal with it well. It took a bit, but he shrugged it off.

The next day Liam got a phone call, which is unusual. It was someone from Merlefest (a major bluegrass festival) telling him he got selected to play in the youth showcase at the festival. Joy returns. Being a parent is an emotional roller coaster ride for sure! But then again, just being a human being is an emotional roller coaster ride. It is impossible to stay on an even track, and would the ride be worth it if we did?

I used to believe one could avoid the valleys and even create a life for my children where they walked as little as possible on those low points of land. But there is no way of getting to the peaks without walking through the valley. And you can't stay on a peak long. Life is trudging through the valleys knowing the next peak is just ahead, if we just keep walking. Life is enjoying the peak while we can, knowing time will walk us down soon enough.

Kenyon Dances

March 11, 2013

Sometimes I hesitate to post videos or photos of Kenyon online. As a person who experiences disability, he is visually marked as an other. I want him to be treated just like everyone else. But when he walks on a stage everyone treats him differently. At a fiddle festival this weekend 400 people in the auditorium fell silent when he wobbled onto the stage, then got behind Kenyon cheering, clapping, and standing in ovation for his

performance. That didn't happen for anyone else. I'm conflicted at times about it. But I've come to accept it as inevitable, and perhaps a good thing.

Kenyon loves dancing. And this space on stage is one of the few spaces he is accepted openly and cheered for being who he is. And I think the vast majority of people don't view it as spectacle, but as being genuinely supportive and loving. We meet so many people who find joy in watching him strive. A newspaper reporter wrote this, "the feeling behind the festival was demonstrated simply with the smiles and outstretched hands of dancers welcoming 8-year-old Kenyon Purcell of Deep Gap to join in." That was it. No mention of disability!

But I think Kenyon does represent the feeling behind many of these festivals. It is not about ribbons and awards, but about the joy of performing for self and others with no expectation of reward, other than the act itself. It is in the doing, in the dancing, in the playing that the joy is found. And I think Kenyon has a gift to teach joy better than anyone I've ever known. I'm really proud of him.

> **GLIMPSE, March 2013:** We just read the last two chapters of *Harry Potter and the Chamber of Secrets* aloud to Liam last night — he was jumping up and down on the couch so animated and so shocked with each revelation as it all unfolded…Phoenix tears! Ginny did it! TM=Voldemort! Sword! Fang to the dairy! Percy and Penelope! Dobby is free!

The Man at Elk Creek

June 30, 2013

What is really important in life? Not second place. Kenyon won 2nd place dance out of a dozen flatfoot dancers at the Elk Creek / Grayson County Fiddlers Convention on

Saturday. Liam won 4th. Think about that — 2nd place! Kenyon! I was trying to process the fact Kenyon placed 2nd among all those older kids and he placed higher than his older brother, when Kenyon and I walked together to find Liam, who had run off to jam with some old-timers at the back of the campground. A big, burly man some 10-years older than me chased us down.

He said, "hey, I saw your son getting that ribbon and wanted to tell your son he did good and give him this $10 bill." My hackles went up. Believe it or not people try to give Kenyon money a lot. Usually $1. Harmless. But sometimes more. A lady at another fiddlers convention asked to buy Kenyon a shirt then told Liam she was doing it because his brother "had a serious problem and she felt sorry for him." And that is why it upsets me, because I think most people do it out of a sense of pity. Kenyon doesn't have a problem. He doesn't need fixing. He is perfect just the way he is. I had a chip on my shoulder.

Three times I told this man we didn't want his money. I did it kindly. Then he said, "It's just that I had a son with Down syndrome who died when he was 11. It would mean a lot if you could take this and just buy your son a gift with it. I know it's silly. But just take it." I humbly took it. And then I listened to his story about his son, his birth, his struggles, his joys, and his untimely death due to a heart complication. Kenyon gave the man a big hug. We parted ways. I didn't even get his name. I was struggling to understand why Kenyon got a 2nd place ribbon out of all those outstanding flatfoot dancers. Now, I know why.

So that man could see Kenyon getting that ribbon, and track us down, and connect with us, and for a moment remember his son and tell his son's story. His son's death was unexpected. A stitch that held his a hole in his heart together didn't hold. He died at 11. Kenyon is almost 9. And I know this man still has a hole in his heart from the death of his son. You could hear it in his voice and see it in his face. But I hope that short moment with Kenyon giving him the $10 and getting a hug helped put a stitch back in that hole in that man's heart. Life is more connected than we think.

One person's choice affects so many other choices and each builds one upon another. Sometimes we never know how one simple choice affects other people. We all have metaphorical holes in our hearts from our losses in life. We can't stop those holes. When we make good choices to be kind to one another, to listen to each other, to stand up for one another, to honor our connectedness to each other, we all put a stitches back into those holes that hopefully will hold. When you have kids in sports or music or other competitive events you can focus too much on winning. First, second, none of it is really important. It's fun and there is nothing wrong with it. But what is really important in life is each other. Holding onto each other while we can. Making strong threads and doing our best to stitch each other up the best we can after the worst comes. And holding on to the ones we love while we are all still here together.

Uwe

December 24, 2013

In this season of giving we are thankful for Uwe Krüger. He is one of the nicest people we've ever met on Liam's musical journey through life. Our whole family loves

music by the Krüger Brothers, and Liam had met Uwe and his brother briefly several times after shows. But Liam wanted to perform one of their songs for a camp audition, so he wrote to Uwe to ask him if it was ok, and to ask him to play with him for an audition tape. Not only did he say yes, Uwe drove to our house to play with him!

Uwe and his brother are big-time stars, but you wouldn't know it by how down-to-earth they are! Uwe gave Liam lots of good advice on life and music. They also made a very special connection talking about Liam's brother Kenyon. Turns out Uwe had an uncle who had Down syndrome. It wasn't just the musical connection, but the life connection they made talking about family! Uwe's trip to our house was one of our most magical moments of the year. Liam got an email today letting him know he didn't make the camp (super competitive, only take 16 folks). But he was ok. He said it was worth it all to play with Uwe.

Liam Becomes a Teacher, Formally

February 14, 2014

Since both Janet Parrish Purcell and I are educators, it shouldn't surprise me that Liam would love teaching. So, there is only one class offered at the community center this semester that really was a good fit for Liam so they asked Liam if he would be a teacher's assistant in two classes for beginners. He said yes.

Liam is 12 years old. The first class is full of beginning guitar players and they are all younger. The second class is beginning banjo, but they are all significantly older - high school, college, and as Liam described them — "folks your age Dad!" He came

home the first night intimidated by teaching people older than him, but I assured him it would be ok, because the main teacher, Mason, would always be there to lead the class.

Enter the snow! Mason was snowed in last night, so Liam was stuck as the teacher. The first class was combined with other folks, so Liam ended up working one-on-one with a younger kid who wanted individual help. That went great. Liam asked the kid what he wanted to learn, and the kid said, "a song that is easy, but sounds hard, so it will impress all my friends." Perfect! Liam taught him "Guitar Boogie."

The second class only had two students show up — one older than Liam and another much older. Liam said it was going pretty well, except the younger of the two kept texting. So Liam asked as the student was texting, "Why don't you play that lick back for us." The student said he didn't hear it, but he got the message and put the phone down for the rest of the class. That is exactly something I would do, and something I'm sure Liam has heard me tell stories about. Liam said he was able to teach them an entire song in the 45-minutes.

Liam absolutely loved it! He was beaming and proud and couldn't stop talking about it. I know exactly the feeling he is talking about it. I can remember feeling that way as a camp counselor and can remember my first class taught at Appalachian 14 years ago and the classes I taught earlier this week — it's all the same feeling! It's a very addictive feeling to help another person learn!

I say it was Liam's first *formal* experience as a teacher. Truthfully, he has been practicing these skills with Kenyon for a long time! He has even taught me on banjo and

his mom on dulcimer. But it is different when you are teaching strangers or students you've just met. Family is forgiving. Students are not! I'm glad it went well for Liam.

Who knows what Liam's future holds, but I think two things he loves are people and music, so it seems that might be a possible direction for him one day. And Liam's had so many great music teachers over the years to set good examples! It is fun to watch these life experiences unfold for him!

Deschooling Janet

February 14, 2014

Janet taught in public schools for 18 years. She quit officially, Feb. 13, 2014. Valentine's Day 2014 was her first official day home as a stay-at-home mom. Truthfully, we had split the role of stay-at-home parents mostly equally over the previous 12 years, though she was always the daytime worker bringing home the big bacon, and I was always the moonlighting stay-at-home dad taking care of the kids during the day and attending graduate school or teaching at night. My landing a full-time position at Appalachian State helped solidify our confidence in her giving up her job, even though mine did not pay as well, but no matter what the financial sacrifice was going to be, we had decided we would make it, even if we had to downsize and move.

Our experience with our children in public schools certainly played a big part in her decision to leave. She said she was never as happy teaching there afterwards because of what we went through. That wasn't the only reason. Increasingly, her job as a special education teacher became more and more focused on paperwork, lawsuits, committee meetings, and less and less interaction with children as a constant rotation of leadership at

her school and the central office left her at work feeling school was both chaotic and unpredictable. The negatives in school, however, didn't even compare to the lure of what was outside the school walls.

Some six months before she left, in August of 2013, we found ourselves at a small fiddle festival in a beautiful mountain hollow in eastern Tennessee. The weather was cool and sunny and we were having the best weekend listening to music, dancing, eating, and being in fellowship with the old-time music community that often gathers in remote places like this to celebrate these centuries-old tunes played on fiddle, banjo, guitar, and bass. All four of us wandered down the river and spread out on the beach of smooth rocks. The stones were warm from the sun, the Black-eyed Susans nodded above us at the top of the bank in the gentle breeze and that warm late-summer sun beat down on us in a good way. Liam was building a dam out of rocks. Kenyon was throwing rocks in the river, cackling with each splash. It was one of those rare moments when all felt right in the world.

"I want to do this every day," Janet said.

"Sure, let's do it," I responded.

"No, I mean it," she said. "I don't want to go back to school. They are growing up and will be gone in the blink of an eye. I don't want to sacrifice any more of life to that school. I'm trading the best days of my life, the best days of our children's lives, for what? I can teach when the kids are grown. I can teach when we have an empty nest. I can never get today back and a day like today can't happen if I'm not here. You three can enjoy this and do this, but I can't if I'm at school."

"It’s not as fun when it’s just us three," I said. "Well, it’s fun, but not as fun."

Liam held up a frog he caught.

Jan continued, "I know we need the money and the health insurance, but surely we can figure something out. I just don’t want this perfect day to ever end."

"I don’t either," I said.

"It’s not just about us," she said. "I can’t treat families and children the way we were treated, the way Kenyon was treated. I tried to change it and I can’t, so I just can’t be a part of it anymore."

After 18 years as an educator, three-times teacher-of-the-year, two-time nationally board-certified, achieving her Master’s degree, and hands-down being the best teacher I’ve ever met, she was ready to hang it up and quit. It wasn’t because she doesn’t care about the children and families — she did. It was that she couldn’t continue to participate in the oppression of her students.

It took six months for us to figure out how to make it work financially to get Janet home. But we did it. And she’s been home ever since.

First Place Dance

March 3, 2014

Kenyon won first place flatfoot dance at the Tommy Jarrell Festival in Mt. Airy on Saturday. This wasn't the Special Olympics or a separate dance where *typical* children are in different categories, not that there is anything wrong with those events, but like all fiddler's conventions Kenyon is included right alongside everyone else, which is reaffirming to one of our life's guiding principles — that the experience of disability is

natural and even beautiful and that we should all make welcoming spaces for all people in our lives.

That said, in the past Kenyon's audience-pleasing, inspiring, and unique dances have won him 2nd and 3rd and 4th place and yes, last-place finishes, but at several festivals he has placed ahead of his typically-abled peers including beating his brother many times! And that was the case on Saturday, there were only two contestants (which I'm proud of my boys for being proud and confident enough to show that men/boys can and should dance!) and Liam took second place and Kenyon took first place. And some folks might roll their eyes — big deal, taking 1st place when there were only two competitors. But in a world that often brushes people who experience disability to the side, this affirmation is a big deal to us. To me it shows that the judges here and at many other festivals understand that it is all about more than competition — it's about competing. And Kenyon always competes with joy, determination, goodwill, sportsmanship, and love. He really just LOVES to dance to old-time music and he was rewarded with a first-place trophy on Saturday.

We seek to live our live in spaces where people reach out with welcoming arms to Kenyon. And not every space is welcoming. The public school system certainly wasn't, so we found a welcoming space in homeschooling. We've been in restaurants/bakeries/stores that are not, so we boycott those and spend our money where people welcome Kenyon's presence. We've been to four sporting events that used offensive images or blasted lyrics with the *R-word* making us feel unwelcome, three of those apologized and we've returned, one defended their choice and we'll never go back.

But that is our life — trying to advocate for respect, but turning away from those who do not welcome all of us, and spending our days in those rare and wonderful spaces where Kenyon can be Kenyon, beautiful Kenyon, wonderful Kenyon, welcoming Kenyon who always responds with love. He has something to teach all of us. He is my role model and my example of how I would like to live my life.

Honoring Brian Friesen

April 29, 2014

Brian Friesen died when he was 9 years old. Brian was helping his younger brother color when he was overcome with a severe headache. Within a day he died from a brain aneurism. Since 1995, Brian's parents have honored his life by giving a professional-grade banjo to a promising young banjo player who might never have a chance to play such a quality instrument as such a young age. This year's winner was Liam. You can't apply to win. The award is not promoted or advertised. A secret committee of folks watch for young players and nominate them. We didn't know until right before MerleFest. Liam didn't find out until he was on stage and the president of Deering Banjos, Janet Deering, brought it to him.

Liam got to play six times at MerleFest. The fifth time was at BanjoRama with some of the all-time banjo greats from Pete Wernick to Jens Krüger to Mark Johnson. Liam took a break on Cripple Creek with them all on stage. Then he played clawhammer during a duet with his friend Micah on mandolin. They played *Christmas on the Mountain* written by one of his banjo teachers, Dick Wilson. Then Janet Deering and Pete Wernick presented him the new banjo. Immediately after, Liam had to get on a golf cart

and hurry to the Cabin Stage where he played and performed on this new banjo for the first time — he played *Jack of the Wood* by the Krüger Brothers in front of the big crowd.

I'm so humbled and honored. I know Liam feels the same. Liam is very empathetic and we are all touched by Brian's story, especially his love of music and the banjo, and that he was helping his younger brother when his aneurism occurred.

Liam's younger brother Kenyon has a brain condition called hydrocephalus. Liam has spent many long hours in children's hospitals as Kenyon has gone through brain surgery, MRIs, etc. I think one reason Liam is empathetic and cares about children is because of Kenyon and his condition. I could never begin to understand the pain the Friesens went through after Brian's death. But we are very aware that this could be Kenyon's fate if his shunt fails. We don't talk about it aloud a lot, but we are very in tune to it. I pat Kenyon's head every morning to feel the shunt that keeps him alive. I'm very thankful, but it is always a bittersweet thing because I know this shunt is the only thing keeping him alive and that he may die early. Kenyon also has Down syndrome which is another reason I think Liam is good with children. He has always helped us give care to Kenyon and I can see that care extending to other children now. From reading about Brian it sounds like he had a great caring not only for music, but for younger kids, too.

Liam teaches the beginning guitar and beginning banjo lessons in our town. For guitar he has a group of 5-8 year olds. There was one little girl whose guitar was full size, but she needed a half size. Liam's first guitar was a cheap Oscar Schmidt half size (maybe $75), but it has great sentimental value since it was his first instrument ever. He asked if he could take the guitar and give it to this girl so that she could learn on a good

instrument her size. Of course we said yes, but this is yet another parallel and connection of what the Friesen family is doing to honor Brian's memory.

Ironically, Liam saved up his own money he earned from playing on the streets of Boone to buy his first banjo (he rented one before that). He bought it at Merlefest from the company owner and founder Janet Deering two years ago. He bought the cheapest, entry-level Deering Goodtime banjo they had, I think she sold it to him for exactly how much money he had saved up $300 or something near that price. He has loved that banjo ever since. It was so cool that Janet was there to present the new banjo to Liam.

It was very cool that Pete Wernick presented the banjo. Pete has been a mentor and friend to Liam since meeting him a year ago. Pete is like a banjo grandfather/godfather to Liam.

Here is an example of how this banjo is really going to make a difference to Liam. He has been learning Kruger Brothers songs, one in particular called "Jack of the Wood." His current Goodtime Deering banjo won't play the highest notes in tune, so he has had to make adjustments to the bridge to get the notes out, if that makes sense. He is going to be amazed to be able to play the instrument and not think about the limitations of what he can play because of the instrument. We couldn't support Liam in his music without others like Pete, Janet, and the Friesens.

The Angels Sang and Blew on Their Horns

July 29, 2014

Happy birthday Kenyon! Kenyon's 10th birthday was Saturday. GRAMMY winners Cathy Fink and Marcy Marxer sang to Kenyon and the other birthday folks

Saturday at the Ashe County Blueberry Festival, where Liam and the band Strictly Strings were playing. The song really captures Kenyon's spirit: "the angels sang and blew on their horns, and they danced, they danced, they smiled and raised up their hands, on the day that Kenyon was born."

Those of you who knew us when he was born, know what a tough time his birth was: premature, learning about Down syndrome, and most of all hydrocephalus which required a 5-hour brain surgery at 5 pounds and 5 weeks of age. I couldn't have imagined 10 days or 10 months down the road, much less 10 years. Over those 10 years we've endured a lot from folks, mostly well-meaning (though misguided) medical professionals, educators, media, and strangers who've insisted on trying to re-make Kenyon into their preconceived notion of what *normal* is…it always starts with how we should *fix* him through surgery, therapy, segregation, medication, or whatever, and after a decade we've seen it all from pity to anger to fear of Kenyon: the angry therapist after we rejected *sabotage* therapy where we were asked to withhold food until he hit a red button, pity from strangers like the one who gave Liam $20 and told him to buy a present for his brother with the *problems*, and the fear we see in people's faces as we walk hand-in-hand with Kenyon downtown or at the mall or at a festival, and the quiet whispers that follow as we pass. The negative parts of raising a child who experiences disability is something we try not to focus on, but something we deal with on almost a daily basis. It has caused us to withdraw a bit from society and cling to those who offer support and love. I would be remiss not to note this negative side of the past decade.

But there is another side. I love Liam and Janet, but I don't think there has been any greater source of joy in my life than Kenyon. Those who take time to shake hands with Kenyon, or let him sit in your lap, or hug him, or kiss him, or let him kiss you, even on the lips or sing with him or dance with him, those of who have spent time with Kenyon know this joy. Kenyon's laugh and touch are healing, spiritual experiences that I can only compare to being in the presence of an Angel on earth. He knows no prejudice and accepts and loves everyone and is willing to share his joy with others. If you've seen him dance, you know what I mean.

A quick example of hundreds I could share: last week Kenyon and Janet came across an older couple sitting on a bench. The older man was disheveled, misshapen, unkempt, and angry. Kenyon stopped and wanted to touch him on the face. He did. Kenyon stroked the man's cheek, pressed against his body in a one-side hug. The man yelled at Kenyon. But Kenyon insisted on trying to touch him. The lady explained that her husband had Alzheimer's and that they rarely left the house. Kenyon knew no fear, no pity, no anger, just love. When the man would let him, between fits of the man yelling, Kenyon touched his face and hands and loved on him. When the man told Kenyon he didn't want any more hugs, Kenyon went and hugged his wife, then smiled back at him. Kenyon's intelligences are many and deeper than I've seen in most others who don't experience so-called intellectual disability. Kenyon has deep emotional and empathetic and compassionate intelligence. He has an intelligence for joy. He has an intelligence for acceptance.

What's a life worth? When Kenyon was born, he spent a month in the hospital, underwent brain surgery…racking up nearly a quarter of a million dollars in medical bills. Since there have been countless therapists, medical follow-ups, surgeries, etc. Is the life of a baby with brain damage from hydrocephalus plus Down syndrome plus prematurity, was this a life worth this kind of investment by society?

As a family we've spent untold hours on Kenyon's personal care with little to no respite. We plan our days and travels and lives around Kenyon. Almost every decision we make starts with its impact on Kenyon. We've given up many personal ambitions, hobbies, friends, dreams, and wishes for Kenyon. Kenyon can't really be alone, so we've arranged our lives so that one of us can always be there with him. After 10 years of living like this, is it worth it?

Of course the answer is yes! I don't want to be a martyr, but I do want acknowledge that it hasn't been an easy 10 years, and that society has often made it harder than it should have been. That said, at the same time, I have had the privilege of living up close and personal to a beacon of joy that counteracts the evils in the world and makes the world right as rain. Kenyon provides an example of how to live life to the fullest, how to experience unashamed joy, how to love unconditionally, and it is an honor to be in his presence day in and day out.

And it's not just Kenyon, but the way good people celebrate with him like so many of our friends and family who unabashedly dance, play, laugh, and sing with him and us.

Cathy and Marcy sum up what I'm feeling at Kenyon's 10th birthday with the lyrics "the angels danced on the day Kenyon was born." Perhaps angels can see 10 years further than we can. Ten years later I know why they danced, because Kenyon has made the world a much better place by his presence here. And so have the people in our lives who have danced with Kenyon both metaphorically and for real out on the dance floor!

I don't know why I write these things. Maybe there is someone right now sitting in a waiting room during a baby's brain surgery, or someone is receiving a diagnosis of Down syndrome or hydrocephalus, or someone has a preemie, or all three, or anyone who is in confusion and despair during the birth of a child. Maybe they will read this and it will help. Maybe they will find comfort in the fact that angels dance on the day every child is born. It will be ok. Ten hours becomes 10 days, 10 months, and 10 years. Happy birthday to my 10-year-old boy! I'm so glad you were born. I'm so happy that you are who you are. I love you!

Cathy's Cancer

"Dad?" Liam asked. "Is grandma going to die?"

I knew the answer. I wanted to lie. I really did.

"Yes, son," I said. "I'm sorry."

In a way, Liam was not my first child — my mother was. As early as I can remember, I felt I was always parenting her. I stayed up late worrying about her and waiting for her to get home. I tried to help her eat well. I talked to her about quitting smoking and drinking. I tried to help her manage her money. I cooked, cleaned, and took care of the yard. As I turned from an elementary school student to a junior high student, I

began to resent her for the life she helped make for us. I began to realize our lives and our relationship were not normal. I left her at age 12, but she never left me, really. Like a shadow she was always there. As an adult, I tried to help her, perhaps tried to save her. She was always in crisis. Just before Liam's birth, we let her move into our house hoping that by living in close contact we could help guide her life decisions and bring her a different type of life. It didn't work. It only brought the chaos of her life into our own. And now we had a child. Liam deserved a life free from the burdens of the past. I wanted to break the cycle. I felt I had escaped the life my mother led, and her mother before her, and who knows how far back these struggles reached. But I was determined to give Liam a shot at a different life. I didn't want him burdened by a history he didn't need to know.

Cathy moved out and into public housing. It wasn't long before she was kicked out and back on the streets. She moved back to her hometown of Greensboro. We would visit. Short visits. We'd send photos, cards, and notes from the boys. She got to know Liam and Kenyon, though from afar. We'd send money. We'd help. But her life remained chaotic until the end.

She got cancer. Beat it once. But not the second time.

Rock Creek

Oct. 9, 2014

My mother, Cathy Anne Purcell, died today. She battled breast cancer for more than two years. She turned 63 last Saturday. Over the summer her cancer moved into stage 4 and spread to her lungs. She was in hospice care, but had spent the past month in the hospital after what the doctors thought was a stroke, but they said it could have been

the cancer spreading into her brain. I guess all those details don't really matter, other than to say we've know this day was coming since the summer. It is still not any easier though.

Our final visits over the past few months were good, knowing the end was near, we were all able to make some peace and say goodbye over and over. We got to see her last on Sunday and it was a good visit. She was able to say "I love you" and was able to hear it too before slipping into sleep from the pain meds.

My favorite photos of her are from her youth. I think those were her happiest times in life. I really love the ones of her from elementary school. She was a very stylish and beautiful teenager and bride and through her early 20s. Those early years were good to her.

In a way, I feel I was more of a parent to her through most of my life. In her 20s she began a struggle with bi-polar disorder that led to off and on addictions that cost her her marriage, children, and home, and left her struggling in poverty for most of her adult life. She lived with us for many years until her addictions became too dangerous and threatened the safety of my home and family. It's a strange thing to reconcile here in death.

Anyone who has tried to help another with addiction and especially combined with mental health issues, knows what an often impossible battle it is. Now that she is gone, so will the late-night phone calls, or officers knocking on my door, asking me to sign papers, letting me know where they found her, what happened, asking me to come pack her things, find her another place to live, or to come testify in front of the magistrate. It was a long, strange trip. I often kept all of this secret from folks.

This might be a shock for some who only knew sweet Cathy. But in death, I think it is important to acknowledge that life on earth is not always easy and rosy. I don't know why I'm even typing this now. Other than to acknowledge her time here was often troubled and sad and lonely despite the efforts of those around her to help. I don't blame her. As always, I am and was just sad I couldn't do more to help. I guess my point is that if anyone deserves to go on to a more peaceful afterlife, however you define it, it is her I think. She had much happiness in Jason and me, and her grandchildren. But those moments always seemed fleeting among her many struggles. I hope wherever she is now that she is at peace and at long last at rest.

Heaven for her, I imagine as the farm she grew up on with its endless green fields of tobacco, stands of tall pine, acre upon acre of untouched woodland chockfull of deer, squirrel, and quiet streams. I imagine her there as a child, barefoot, in a summer dress, rambling through rows of corn, singing, innocent and carefree and unencumbered with the messy realities of life. I see her sitting on the edge of Rock Creek on a hot, summer day cooling her toes in the clear water. I know the spot. It's the same spot I'd escape too as a child. I grew up on that same farmland. She told me about making that journey to Rock Creek as a child and I often went there myself.

Cathy donated her body to the UNC-Chapel Hill medical program. In a year or two, when the medical student who is paired with her finishes his/her study, we will receive the cremated remains of her body. Over the course of my mother's cancer I've been thinking about where to spread her ashes. If I could I'd go to the old barn, hitch a strong horse to a gray tobacco sled and parade her down the narrow farm road along the

cornfield through the stands of pine to the back fields of tobacco where the road turns to a trail that cuts steeply down to the banks of Rock Creek, well, I'd do that. But all that is gone. Half-a-million dollar homes and tennis courts and paved cul-de-sacs have long turned that magical farm into another cookie-cutter development. I still might go and see if I can find any water, any rock, any semblance of that magical place we both found refuge in during our childhoods. I think she would be happy there.

Go be with those you love and tell them so. Try to help those who will let you. Find your own Rock Creek and treasure it. Time is truly fleeting.

A Dancing Crocodile

For Kenyon fiddle festivals meant dancing. He danced in competitions and he danced for fun. But between 2014 and 2016 he began to lose his ability to walk. It was more of a tiredness at first, but then he began falling. He entered physical therapy, but the pediatric orthopedic doctor we saw at one major university hospital told us he would continue to decline and never really walk again.

One of his first mobility assistance devices was called a crocodile. It is like a typical walker with a fold-down seat one might spy at a nursing home, but it faces the opposite direction and instead of institutional silver came in jet black.

As Liam’s band Cane Mill Road performed more, we began to attend fiddle festivals less. But we did make time to return to one of our favorites- Laurel Bloomery in Eastern Tennessee. We didn’t quite think through how Kenyon might respond to the dance competition. We watched folks compete all day on all the instruments and then the band competition and Kenyon had a great time. Night was upon us and the called out for

contestants in youth dance. Kenyon heard the call and struggled to get out of his chair and into his crocodile to go compete.

We were caught a bit off guard. He couldn't stand without assistance any longer. He definitely couldn't stand on the two and half foot rectangular dance board to compete. Nonetheless, he persisted.

Kenyon rolled his crocodile onto the concrete and got in line to dance. His favorite old-time band of all time, The Slate Mountain Ramblers, were playing the music and it was a fast and furious version of *Fly Around My Pretty Little Miss* with the fiddle strings flying and the clawhammer banjo ringing and the bass thumping. The kids took turns dancing on the board in flat foot style stomping to the rhythm of the music, keeping their upper body rigid and straight, but letting their feet fly.

Kenyon was last in line. I'm not sure anyone realized he was competing. The music had stopped and people were talking. He rolled up to the board and there was dead silence. I wanted to go help, but he had already denied our help several times and shoved our hands away. It was clear he was doing this on his own.

He struggled several times to get his walker up on the board. People from the crowd started coming forward to help, but he put his head down and with a huge push Kenyon managed to straddle the board with one wheel on and three wheels off and the fiddle player, seeing him on, struck into the fiery tune and the rest of the band joined in a raucous version. The crowd erupted in cheers and Kenyon stood up holding firm to the walker's handles and began lifting one foot at time. He wasn't dancing like the Kenyon of old who dazzled the crowd with his twirls and fancy moves, but he was dancing, one

foot at a time, he was dancing, and the crowd cheered louder and louder, and the music went around twice before the fiddler called out, "everybody join in" and kids, parents, old timers, bearded hipsters, young couples, long haired hippies, and all the varied types of people you find at festivals like this hit the concrete floor joining Kenyon. Several folks threw down more boards. Dogs trotted through. Someone grabbed Kenyon and spun him around in his crocodile. The music continued late into the night. And Kenyon eventually tired and we loaded up and headed home. He didn't win a ribbon that night, but he won the hearts of everyone there. And he won me over as one of the bravest and most determined people I've ever known.

North Carolina State Champion

October 28, 2015

Liam won what is the highest honor at the N.C. State Fair Folk Festival — the Bascom Lamar Lunsford Trophy for the individual or group that best exemplifies North Carolina's musical heritage. And not just for youth, but for the whole 10-day competition for adults and groups and bands. Liam, a 13-year-old, best exemplifies our state's music heritage? Could that be true? We never imagined it going in... we just wanted to let him perform and eat some fried Oreos, see the giant pumpkins, then puke after riding the Tilt-A-Whirl.

I'm very proud Liam has chosen to keep this music alive and happy that he loves to play and perform it. I hope he can find a way to make this his life because it makes him so happy to play and sing for people. And thankful for all the good people in bluegrass and old-time music who have made him who he is with your positive

influences! And proud to be a North Carolinian too! He played *Gold Rush* and sang *Freeborn Man* at the festival.

Liam wrote this on his Facebook page and I think it's from the heart, but I can't help thinking that he understands social media strategy and public relations better than the college students I teach on those very subjects. I talk about class a lot at home with Janet, and I guess he listens, even though he might appear to be reading, playing, or watching something on TV. When I read what Liam posted online, I thought, Liam would be great at public relations. But I think it's more than that. I think he is just a thoughtful person and as we get used to him having a Facebook page, we are also getting used to reading thoughts we might not otherwise hear articulated. Liam posted:

> Just found out that I won the Bascom Lamar Lunsford trophy at the NC State Fair Folk Festival, Raleigh, NC!!! The Bascom Lamar Lunsford Trophy is awarded to the individual or group that best exemplifies North Carolina's musical heritage. It is an honor to have won such an award like many of my mentors and role models. A big thank you to Clay Lundsford, Bascom's nephew, previous Lunsford Trophy winner, Matthew Weaver, and Marsha Harris, 2014 winner of the Annette Pulley award (Annette was my Great-Great Aunt) for all your support over the years, I hope to follow in your footsteps.

Closing a Circle

October 9, 2015

A year ago today my mother Cathy died. She donated her body for medical research and yesterday her ashes arrived. Today along with my brother, Jason, and my son, Liam, we traveled to Greensboro to take her to her final resting place. We hiked through the woods to a remote and secret place along a stream where she played as a

child, where Jason and I played as kids. I haven't been there since I was 13. Liam is 13 and now he completes the circle having gone with us to this spot. I was very happy that it was still there and still as peaceful as I remember as a child. Some of my childhood friends probably know this spot. Janet stayed in the car with Kenyon. It was too far for him. It's still hard to believe she is gone. May she rest in peace. We miss you and love you.

I Quit

Email to my COM Department Colleagues • Sept. 14, 2016

Several folks have asked why I'm not on the teaching schedule for spring, so I wanted to just send out one email to everyone to explain. I am leaving after the fall semester to pursue something a bit different. I really just came to this decision over Labor Day break after getting some test results back about my youngest son Kenyon.

The decision to leave has been one of the hardest decisions of my life. I love working here. I love our students, our department, our college, our university, our town, our alumni, our field, all of you, and everything about my job. I have never been happier in a job and the past 16 years here have been amazing!

There isn't one single reason that I'm leaving, but instead many reasons that by themselves might not lead me to leave, but taken together lead me to make a radical change in my life plan.

The first and foremost reason is my son's health. Many of you know Kenyon (age 12) and the challenges he has faced in life. This summer was transformative in regards to his health and future. We spent much of the summer at Brenner Children's Hospital in

Winston-Salem. Kenyon has always had a different walk because of hip dysplasia he was born with, however as he has grown in height and weight his little hip and muscles around it have not kept up and he has lost much of his mobility. We transitioned this summer to using a walker and hybrid device between a wheelchair and stroller. It's been a big change for him and for us. The doctors say he will eventually lose all mobility in his legs and that he is not a candidate for hip surgery or replacement.

Our trip to DC over Labor Day break confirmed to us that now is the time to make a radical change for Kenyon's sake.

So, while Kenyon still has mobility left in him, my family has decided to take Kenyon on a *walk about* of sorts -- a tour of the country. We are going to pack up in an RV and will take Kenyon to see as much of the United States as possible, while he still has some mobility to do things. We feel this will be impossible in just a few years.

On top of Kenyon's mobility changes over the summer, he also had two seizures, which has never happened before. This too leads me to do this now.

After the first seizure he was unresponsive and we called 911 and it seemed like an eternity that I held him in my arms thinking we had lost him. He slowly came to and around and by the time we got to the hospital he was back to his smiling self.

That experience made me realize how short life is and focused me on what is most important in my life. That seizure, holding his limp body in my arms, realizing that this could be the end...really cemented in my mind how short our time is with those we love and helped lead me to this idea of taking a year off to *walk about* with Kenyon.

Another factor is an opportunity to try being a digital nomad. I've been approached several times over the past few years to do communication consulting work, but have turned those opportunities down. In the new year, I'm going to launch a communication consulting firm (just me) focusing on a broad array of services from media relations to brand management to social media strategy to crisis communication focused in particular on clients in the music industry. I have a couple of clients lined up for 2017. I will be able to do this on the road and I believe I already have enough work lined up to fund our trip for at least a year.

Yet another factor is my other son Liam (age 14), the musician, who continues to book more and more gigs around the country with his band. I really want to give him the support he needs to give it a real try in the music industry.

We homeschool both boys, so what a wonderful homeschool environment to have — the wide open road as your classroom!

What happens after 2017? I don't know. I love teaching/research and can't imagine myself doing anything else for the rest of my life. However, I feel this chance to focus our lives on Kenyon for a year *walk about* to give him a gift that would be difficult if not impossible in the years ahead, is something I must do now or never.

I wish you all well, and thanks for listening!

William Purcell

Cancer Comes in Threes

I thought leaving work would open the door to a grand journey on the road with my family in an epic unschooling adventure. And in doing so, thought it was important to do it before Kenyon's ability to walk changed even more. But life gets in the way.

We had experience with a long battle with cancer. My mother's battles with cancer lasted two years before her death. But cancer comes quickly too. Shortly after leaving my job at Appalachian State, my uncle David was diagnosed with cancer. David and his wife, Elaine, were known as Nana and Papa in our family. They took me into their home when I was 12 and raised me. In way we were lucky that I had quit. It allowed us to spend the last few months of his life with him. I believe the experience is still too close to write about. It's still hard to even think about today.

I do know the sudden and unexpected loss clarified something we as a family had always talked about — time together is fleeting. In a short period of time, we had three battles with cancer. We lost my mother, we lost Uncle David, and during the writing of my dissertation over the past year, my wife Janet had her own battle with breast cancer. She's just finishing up radiation as I am finishing the final words. It's all too close to make sense of through writing now. But the thing I do know, that I can write, is that it all confirms that our choice to unschool our lives and spend as much time together as possible learning and living was the right choice.

Papa’s Death

Facebook Post • February 16, 2017

After the death of Liam and Kenyon's Papa, David Barham, I just wanted to say a sincere thank you to everyone for your thoughts and prayers during the past few months during his battle with cancer and especially the past month during his time in hospice and death, and a thanks for those who were able to come to the funeral and visitation.

There is no way I can respond to all the comments and messages, but I sincerely thank each and every one of you who helped sustain our family through this process whether you sent a card, made a post, brought food, visited, no matter what you did, you made a difference and reminded my family how important it is for us all to stick together in difficult times.

It's been a week today, but it seems like year. Life here goes on, somehow.
In the past few years I've lost my mom, and my uncles Johnny, Charles, Kenneth, Alton, Dan, Aunt Edith, and now David. One of my cousins said that this is the start of a long process of saying goodbye to the generation that raised us. It's true. And we're not that far behind that generation.

Life's circle completes itself, whether we are ready or not. Let's love each other and be good. Let's make the time we have left worth it and our lives worthy of the time we have left. Love to you all. William, and Janet, Liam and Kenyon.

An Update on Kenyon's Health

Facebook Post • November 7, 2017

Those who met Kenyon over the past two years, might not know that at one time he could not only walk and dance, but run. He was just getting to the point of winning ribbons at festivals for dance when he began having trouble. Most folks know Kenyon has Down Syndrome, and a few know he was born with hydrocephalus. But his current issues don't seem to be related to either. Over the past few years Kenyon has gone from using braces on his ankles to special shoes to a special stroller then to a walker, and now he has a blue chair that is a cross between a stroller and a wheelchair. Even now he can stand for a few minutes with some assistance, but it is very limited.

The doctors at Baptist Hospital in Winston-Salem said it is due to his hip dysplasia, which he has had since birth, and that there is no surgery to be done and that he will eventually be full-time using a wheelchair as he gets heavier. So, we went for a second opinion at Duke. Doctors at Duke said the opposite — there is no reason his bad hip should prevent him from walking, that the cause is something else. So, we've had every test imaginable from heart to brain to muscle to bone...EKG, EGG, MRI, and on and on and on...they've ruled out hydrocephalus, muscular dystrophy, etc. We've been to a doctor/hospital nearly 100 times over the past year, mostly in Durham.

We've come to the acceptance that even if they figure out why he is losing his ability to walk, and even if they don't, that we need to prepare for life on wheels. So, we've been doing that. People have asked why we weren't at this festival or that festival. Most of our decisions about where to go are driven by Kenyon — can we get his chair in,

is there a good bathroom that we can get him into...it is hard to describe how Kenyon's care drives every decision in our lives.

Unrelated to him losing his ability to walk, Kenyon has started having seizures. This was super scary the first two times. Ok, honestly, every time. But the first two were extraordinarily scary. We called 911 and he was transported to the hospital. When he has a seizure, he basically faints and stops breathing. He is on a medication that has really gotten them under control, but he still has anywhere from six to 12 a month. One of the three of us always has to be with him in case he has a seizure, so managing that has been a life changer too.

The respiratory issues began after the state fair last year, Kenyon was extremely sick for about two months, through Christmas, was in the hospital once, but a high fever that wouldn't go away and a bad reaction to an anti-biotic. That took months to clear up, but he is back on track, though all that has led the ENT and pulmonary to prompt a surgery on Thursday. Did I mention a sleep test showed he has sleep apnea too? But the surgery should take care of and give relief to Kenyon for these respiratory and sleeping issues.

Anyway, I could go on and on about his medical care, but if you've seen Kenyon, you've seen he is in as high spirits as ever! He really loves life and living life! He is such an inspiration! None of this gets him down, and he takes it all in stride.

We haven't talked to folks a lot about it, because we always thought we'd have some answers after the *next* doctor's appointment, or the next one, or next one, or next one…that hasn't happened.

All this has changed our lives so much. Kenyon changed our lives from his birth, but now we have to rethink everything from our cars to our house to our schedules...every decision we make starts with Kenyon and if and how he can participate.

Knowing his mobility is going down, we decided to make some drastic changes in our lives. I quit my job at Appalachian and started freelancing work, so that I could be at home more and so that we could take Kenyon places, while he was still light enough to carry and lift, and while Liam is still at home so he can help us. We had big goals of traveling the USA to show Kenyon as much of it as possible. It's been slower than we thought, but we've traveled from Florida to New York to Missouri to Maine to everywhere in between.

Some of the toughest parts of this journey has been healthcare, but that is a whole other story. The short of it is that it has worked out fine, but been a battle and expensive, but fine. We couldn’t make it without health insurance, and in particular health insurance that doesn't discriminate against people with pre-existing conditions like Kenyon.

Working from home has been a tough transition, but we've made it work. I did go back to Appalachian this semester, but am planning to take the spring off to focus on freelancing and Kenyon. I'm extremely lucky that I can work anywhere as long as I have internet access, a phone, and a computer. Our goal is still to take Kenyon as far as we can, as long as we can and show him as much as he can see.

When Kenyon had his first seizure, I really thought that might be the end. His body was limp, he wasn't breathing, he was unresponsive...I could barely get the words out on the 911 call. He came around and was fine, but it really made me think how fragile

and fleeting life can be. In a moment the whole world can turn upside down. I can't even think of life without Kenyon. He is such a part of my daily existence. He is such a source of joy and pride. He is a fountain of love.

Kenyon's seizures and losing my Uncle David last February, my Uncle Charles and my mom over the past three years, have really hammered home the idea that life is short. So, we've really changed our lives to try to make the most of the time we have together as a family. And I know that has meant not seeing folks as much, not going to all the festivals, not being everywhere and doing everything. But our goal is spend as much time together as a family as possible and to help Kenyon live a happy, healthy life.

We could not do it without Liam. He is an anchor in our lives and Kenyon's life. Liam does so much of the physical work of lifting Kenyon during his care. But he is also so loving and sweet and helps Kenyon to learn and grown. He is the best big brother ever! Anyway, I need to do this post and let folks know what has been going on in our lives. I hope that helps. Thank you all for your support.

Follow-up post the next day.

Kenyon did great today! He is feeling good, but that may be all the meds! The surgery went well, spent most of afternoon in recovery, was well enough to skip ICU and go straight to the step-down floor, if he continues to eat and drink then might get to leave tomorrow or be moved to a regular room. He is sleepy now. Tonsils and adenoids gone, lung scope showed no signs of anything wrong, stomach scope showed some sort of chronic infection so they did a biopsy and we should hear something back in a week or so. Thank you all for your support, words and emojis really do have a powerful impact on

people, we felt all your encouragement and prayers and so did Kenyon! In all these hours waiting today reading them made a difference. Sometimes when I turn on the news l wonder about this mean old world, but then it is times like these that good words and deeds, faith, and kindness show that they among the strongest tools we have in this world to support each other!

My First Editor

Lynn died this year of cancer. She was my first editor when I was a cub reporter straight out of college working for *The Alleghany News*. I couldn't find the strength in me to write about her when she died. Now that some time has passed its easier a bit. I learned so much from her mentorship and leadership as an editor. I lost track of her after leaving the newspaper, but nearly 20 years later when taking Liam to compete in his first fiddlers convention in Ashe County — there she was as a judge! She took Liam under her wing in the old-time and bluegrass world the same way she did me as a reporter so many years ago. Her heart was so strong for people, music, and animals.

One of my last memories of Lynn was at the small town dance hall the Alleghany Jubilee when Liam was guesting with an old-time band. It was Halloween and the place was packed. Floor boards rattling, dust flying, Liam's fiddle bow burning and churning out that old-time tune as what seems like nearly 100 people flat-footed in unison...it was magical. It was another one of those perfect moments in life. I stood there in the middle of the dance floor with people all around me in costume stomping together on the beat, the dust swirled in the dim lights, the stacked speakers glared the sound so powerfully you could feel it inside your body, a body that was jolted with each beat as the floor

shook, and I stood there mesmerized watching Liam on lead fiddle drive the melody over and over, his eyes closed, his left arm smooth and fast, his fingers a blur — I felt so alive, so real, yet so in a dream. It was perfect.

After the dance Lynn and I talked about how crazy it was that after so many ago working together we'd find ourselves together again in Sparta thanks to music. The old office where Lynn and I had desks beside each other is now Muddy Creek Music Hall. I'll be returning there in August with Liam and Cane Mill Road as they play a show there. It will be strange to think of how many days and nights I worked In that space alongside Lynn learning my craft. I'm so glad my sons got to know her. I miss her and I know so many other people do too. Rest In Peace Lynn!

Grey Fox

July, 2018

> Hey, hey, hey. Holding tight to the tail of a shooting star. Hey, hey, hey. You're running circles around me. Circles around me now.
> — Sam Bush, 2009

One night I walked into Walmart and I saw an older man standing over the peaches staring at me. He walked straight toward me deliberately and quickly as if we were long, lost friends.

"Your right foot, it hurts, right?" he said.

"Excuse me?" I said baffled.

"Does your foot hurt?" he asked again, pointing down to my foot.

"Why?" I asked.

"Don’t think I’m strange, but I see things," he said. "I always have. I can see sort of an aura around people centered on where their pain is."

"Ok," I said looking around for security.

"It’s ok, I just saw yours and thought I might pray over it and see if it helps," he said. "It doesn’t always help, but sometimes it does. It’s just a gift I have."

I didn’t see any harm, so I let him. He grabbed my hands and said a very basic prayer of the sort I heard all the time growing up, only it was focused on my foot, which had been in pain for weeks. He finished. I thanked him. He went back to picking out peaches.

I didn’t think much about it until the next day. My pain was gone. It still didn’t make me a believer. But I have to admit, the pain was gone.

I’ve seen Kenyon do the same thing to people. I think Kenyon can see an aura of emotional pain. Perhaps once a month or so, Kenyon will see someone and try to iniate contact with them. Sometimes I facilitate and sometimes I don’t. While he can’t explain it in words, he often just reaches out and touches their face. He will look at them. He might touch his forehead to their face. He might kiss them. They rarely turn him down. And there is no scientific way or otherwise to really know if he helped. When Kenyon is finished, like the man at the peaches, we simply return to our business of living.

When Liam was about nine years old, a famous bluegrass musician who had been a judge in a competition that Liam had just competed in found me afterwards.

"You Liam’s dad?" he said gruffly.

"Yes, sir," I replied.

"I want to talk to him," he barked. "The boy's got something in him. I can see it. When I was a boy, Doyle Lawson [famous bluegrasser] saw it in me. He took me aside and told me something then that changed me. I want to tell your boy now. It won't be easy to hear, but he needs to hear it. I just wanted to tell you before I did it."

I didn't see a choice. He was determined. And I was new to bluegrass and really didn't even know that Doyle Lawson was a legend. I didn't see any harm in it.

Afterwards the man told me, "the boy is marked. I can see it. The music is in him in a way it's not in other people. He is music and music is him. Nurture it. You hear me? He's got a shot."

"Yes, sir," I said taken aback.

I asked Liam what he had told him. He said it was a lot of criticism about his tone, tuning, timing, and about every aspect of his playing what he needed to work to improve. And Liam said he told him to never stop loving music.

A year later Liam attended a music camp led by one of the founding fathers of bluegrass. This man took me aside during the camp for a similar conversation. He said that even though Liam was only 10-years old, that he was going to be a musician for life.

"But he's not even the best player here his age," I argued.

"It's not where he is now, it's his potential," he said. "I've seen it before. Some kids are just born with it in them. And Liam was born that way."

I had never thought of Liam's path in life other than perhaps him being a teacher. But these two conversations less than a year apart made Janet and I really think about

Liam's future. I think we both mostly forgot about the prophecy of these two men until years later.

We were already doing most of what they were asking anyway. We both loved music and our home was full of music from CDs to a piano that Janet played to lots of toy instruments like drums, horns, tambourines, and such. Liam and Kenyon both live lives centered around music.

For Kenyon every day he spends time surfing YouTube for music. He has his own instruments he plays. He dances, even now in his wheelchair. He loves live music and always wants to be on the front row.

For Liam, since we began homeschooling each day became more and more of a chance to immerse himself in music. We didn't encourage it, because we didn't have to encourage it. It was in him. We did nurture it.

Janet and I came from classical music backgrounds. She was piano minor in college. I was in marching band, but had no talent other than the ability to play whole notes somewhat in tune.

Acoustic mountain music was something Liam learned in an after-school program. We dropped him off there every Thursday for seven years. He teaches in that program now. He learned the basics of playing by ear and had the chance to get his hands on all sorts of stringed instruments in the program. He learned them all.

He began playing on the streets of Boone to raise money to buy his own instruments. His collection has grown to more than 30 instruments, most of which he bought with his own money.

At age 10, when he wanted to attend a pricey music camp, he self-recorded a CD in his bedroom on his Apple computer and sold 100 copies at $10 a piece to pay for camp. He did the same thing for two more albums to fund summer camps.

His interest in recording grew and he began building his own recording studio, taking over the upstairs of our home. Thanks to the continued mentoring and support of an amazing community of musicians around him, he has turned the upstairs into a real recording studio and produced one album there, and recorded much of another one, and has launched his own record label.

He found a community of musicians he immersed himself into from an early age, learning from them as they played music together. He built a band with friends that has grown into a Billboard-charting success.

In short, from age seven to now at 17 music has, just as the prophecy from the two men suggested, been at the core of Liam's life and schooling.

Billy Strings is perhaps the hottest acoustic musician in Americana and bluegrass today. He is Liam's elder by 10 years, but still considered young. The acoustic star sells out venues across the country and tops the charts.

In the summer of 2018, Liam's band Cane Mill Road, played one of the largest and most iconic music festivals in the nation — Grey Fox. Billy Strings was the artist-in-residence, which meant Billy spent much of his time guesting on the sets of other musicians. Billy guested twice on Cane Mill Road sets Thursday and Friday.

Friday night, or really very early Saturday morning, I walked over to Billy's campsite to fetch Liam for the evening. Liam and Billy were playing Doc Watson tunes

with Billy on guitar of course and Liam on fiddle. They both had to be exhausted from the festival schedule and all the fan interaction, but here they were in their downtime, standing inches from each other playing fiddle tunes into the wee hours.

The next day Liam made a bold move. He asked Billy if he could play on Billy's Saturday night set. Billy said yes. Liam spent all day preparing. He talked to Billy's sound guy and learned about the in-ear monitors. By Saturday night he was ready. Billy puts on an amazing dance tent shows. This night the crowed poured out of the tent by the hundreds and into the night air. Dancing, swaying, singing, moving, and grooving both Billy and his band and the audience were in sync. Billy called Liam on stage and introduced him and launched into a wild rendition of *Freeborn Man*. Billy said, "You ready, Liam?" And he turned the melody over to Liam and Liam soared, his fiddle on fire, his long hair swirling as his body flowed with the lines of the music and Billy stood toe to toe with him smiling and nodding, then Billy took the line back and morphed it into a what seemed like a band of demons wailing from inside his guitar and he shoved the melody back to Liam, who energized by this exchange countered with Angelic licks that both complemented and complicated what Billy played, back and forth they went and then Billy mouthed "together" and they played in some strange unison I think no one but the two understood and the crowd on the verge of complete and utter ecstasy bounced and screamed and at long last Billy stepped back into the microphone to finish the last chorus and I stood at the back weeping, Kenyon nearby had both fists as high as his wheelchair would allow him to raise them pumping them and shaking his head back and forth in a wildly violent motion that matched the energy of the tent and stage in his own

way, and I wept, and I knew at that moment that all I could ever do in raising my children in teaching them anything, in unschooling them, in living with them and learning together, that it is all about trying to hold on tight to the tail of a shooting star. That is all that parenting is, holding tight as long as you can and then standing back and watching the star sail, glow, and light up the night sky. In both Liam and Kenyon I have shooting stars, each in their own way, and I continue to hold tight, but I know my grasp will eventually fail me. But for now, just a little longer, I want to bask in that sweet starlight and know that I had some small part in making the deep, dark night, a brighter place for the world.

CHAPTER V

ANALYSIS

I believe this autoethnography meets Kincheloe and McLaren's (2008) notion of critical theory as an evolving criticality which resists concrete foundations in favor of an ever-growing articulation that is responsive and searching for new connections and new ways of understanding everyday life and human experience. If learning is, as Illich (1996, 1971) posits, simply a matter of living everyday life, then the narrative I wrote details not only a new way of understanding the everyday life of homeschooling as unschooling, but one human experience of doing so, in particular through the lens of deschooling and disability.

Bronner (2011) suggests critical theory is fueled by desire for liberation. Our family's story of our ongoing quest for liberation, a space we have not yet completely found, though certainly unschooling is as close to a space of liberation we've discovered, is an example of radical practice that could lead others to similar paths of emancipation. However, as Kincheloe and McLaren (2008) explain evolving criticality, "critical theory is never static; it is always evolving, changing in light of both new theoretical insights and new problems and social circumstances" (p. 407), at the end of my research I'm left with the idea that the knowledge I've created on these pages is contested in light of the the insights from looking back upon the forces of its construction and constraint.

Privilege

Using Phillips (2000) idea of *contested knowledge*, as a scholar I apply critical theory as s tool by articulating various social, ideological, and historical locations of the researcher, researched, and research act. Critical theory works to confront two forces: that which seeks to produce it; and that which seeks to constrain it.

Society works to normalize privilege, to hide privilege, and even silence it (Twine & Gardener, 2013; Iverson, 2007; Howard, 2004; Ladson-Billings, 1998). While I do address privilege in several locations in the research, I failed to fully analyze and address how privilege produces and constrains my research. This is one-way privilege works, by making it difficult and challenging for the person experiencing it not only to recognize it, but to address it. Rodriquez (2009) writes:

> Many whites have not been taught to see their privilege, to understand its significance both personally and socially. To be sure, quite the opposite is the case: they have been carefully taught not to see it. (p. 98)

The apparent absence of privilege to those who benefit from it becomes one of the ways privilege works to reproduce itself. Twine and Gardener (2013) challenge researchers to become aware of the ways privilege hides itself, especially white priviledge, citing Soja (1989):

We must be constantly aware of how space can be made to hide consequences from us, how relations of power and discipline are inscribed into the apparently innocent spatiality of social life. (Soja cited in Twine & Gardener, 2013, p. 108)

McIntosh (1988, cited in Carr & Lund, 2009) points toward how privilege works, as it did in my research and does in many white lives on a daily basis, "white people…need not reflect on their whiteness in a range of daily activities, ultimately demonstrating the unearned privileges of being white" (p. 53). Privilege is the unearned advantages granted by society to some people, but not others through structures and systems, and there is a long list of those who experience privilege and those who don't based on a variety of factors including, but not limited to: race, gender, sex, religion/or lack thereof, disability, nationality, sexuality, class, body type, and education.

Built-in biases and social norms in society's systems privilege some and oppress others. A simple example my family faces every day is the physical layout and construction of buildings. Most buildings are systematically constructed to privilege the abled body. I have to research, think, problem-solve, and often take the side door, back door, or even physically carry Kenyon, in order to access many buildings, while privileged bodies simply walk up the stairs, through the narrow door, because the building was not designed for all people's equal access, but only for those with certain types of bodies.

In the same way privilege operates in this research. My autoethnography is textually-based and written in an academic language that makes its ideas inaccessible to many, including Kenyon and others like him who experience intellectual disability. It privileges those of a certain educational level and those who learn best through textual discourse. Other researchers have found ways to address this privilege, such as Harrington (2017), who created a graphic-novel style chapter in her dissertation to open

her research to scholars with intellectual disability, the very scholars she was researching. Harrington's multimodal approach is one this dissertation, and many others, could benefit from to open the knowledge work to as many other people as possible. Most research in the academy, including my own, privileges those with access to colleges and universities where increasingly the knowledge created on campuses is hidden from the public through firewalls involving paid access, subscriptions, and pay-per-use. I encountered this in my own research when finding articles on databases that neither UNC-G nor Appalachian State University could grant me access to through library access.

Privilege is not one dimensional, but intersectional, meaning various aspects of identify contribute to the oppression or privilege in a variety of ways from amplification to contradiction. Villaverde (2008) defines intersectionality: "the way sexism, racism, classism, ageism (and any -ism) intersect in lived experience, brining awareness to the varying degrees of oppression in layered structures of power" (p. 55). For example, as a first-generation college student, raised in part by a single-mother in poverty, there are oppressive aspects of that working class existence that works to oppress because of the way I talked, walked, dressed, thought, and systematically how a lack of financial capital and social capital worked to keep me in the same social status as my mother — poor and working class. I write about this in depth in this dissertation. However, so to does privilege work to my advantage, especially as a white, heterosexual, male. These identities work in contradiction to my identify as a child of a working class, single mother in poverty, and allowed me enough privilege to escape one station in life and move into another more privileged one. I write about this in depth, about working to escape the

poverty of my childhood, working to succeed in school, working to graduate from college, working to learn the rules of how to speak, dress, eat, act, in certain circles to advance my station in life to a middle-class existence thereby seemingly escaping the life of poverty I grew up in, however privilege often hides itself by cloaking in the idea of meritocracy where the credit for this rise was my own hard work, skill, and effort.

I bought into these often-Americanized ideas of meritocracy for years and thought of my life as one of overachieving and overcoming great odds to achieve and therefore enjoy the fruits of my labor: my job, my home, my car, my family, my life. However, upon entering my graduate program, I began to read, meet, listen, and interact with others who opened my mind to the idea of privilege, an idea I continue to struggle with, and will all my life, because society, for now, is set up to privilege most all of my personal identities, with the exception, perhaps of lack of religion and disability. But even those two identities are not that simple considering intersectionality. Nevertheless, because of the intersections of whiteness, maleness, and heterosexuality that *layered* together in a way that allowed me to navigate the existing *structures of power* in a way that simply led to other privileged identities — education and class. Not only my own whiteness, but that of my surrounding family, community, church, schools, and work gave me an unequal advantage. Often this worked through mentorship where individuals came into my life to show me a way out of a working class existence to a path toward a middle-class one.

Being white, male, heterosexual, and able-bodied worked in racist, sexist, and ableist ways by providing a system of advantages that allowed me over others to access people, places, and privileges that eased my path while oppressing others who did not

experience such privilege. A good example is the country club near where I grew up. Although my family didn't enjoy enough privilege to access this white space of tennis, golf, horseback riding, dining, and socializing, my own privilege allowed me to befriend others whose families did. These friends not only taught me the rules of dress, speech, and etiquette of both the social and dining spaces, and the games these rich, white folk played from golf to tennis to polo, they provided me physical access to these spaces to practice these skills. Reflecting on this experience growing up reminds me of Jennings and Lynn (2005) who describe, "well-meaning whites who wish to contribute to those who they consider to be less fortunate" (p. 26). Though Jennings and Lynn were writing about race, I see the same dynamic in my story in regards to class and I enacted what the two researchers describe as a rule of power:

> Those who are not participants in the culture of power are better enabled to participate if they are explicitly aware of the rules that govern the rules of power. Members of cultural groups often transmit information implicitly to one another thus making it difficult for non-group members to negotiate the culture of power. (p. 26)

Though I was the *less fortunate* one in terms on one identity, class — without being white, male, heterosexual, able-bodied, and perhaps assumed-to-be Christian, I could not have accessed these white spaces.

What I learned there certainly helped me learn the rules of power to navigate college admissions, scholarships, internships, and later hiring, promotion, and networking in the 1980s and 1990s South where systems of privilege and access were and perhaps still are, entrenched in good ol' boy networks of white, male privilege. Bourdieu called

this cultural capital (Sullivan, 2002) and suggested that even if lower class individuals could climb the social ladder, this advancing is in itself oppressive because it reinforces the idea of meritocracy, rather than challenging it. Sullivan (2002) writes:

> Bourdieu's view is that cultural capital is inculcated in the higher-class home, and enables higher-class students to gain higher educational credentials than lower-class students. This enables higher-class individuals to maintain their class position and legitimates the dominant position which higher-class individuals typically goes on to hold. Of course, some lower-class individuals will succeed in the education system, but, rather than challenging the system, this will strengthen it by contributing to the appearance of meritocracy. (pp. 145-146)

Though these experiences took place thirty years ago, the effects of those privileging systems multiplied over years privileging my access to information as a reporter, privileging my promotion to editor, privileging my access to insider information working in public relations for a university, and privileging my hiring as an adjunct twenty years ago despite no graduate work. Looking back at my life it is easy to identify the privileging identities that eased my path over other people in a way that gave me an unfair advantage because of being white, male, heterosexual, able-bodied, and perceived to be Christian.

As a child, my aunt and uncle took me into their home providing me with a stable environment from which to launch into college and in that launch, even as a first-generation student, was easier because of being white, male, and heterosexual. Sure I had struggles, but those struggles were easier than for others whose identities were not and are not privileged by society and by the systems that govern us every day.

An example is my best friend from today and from my undergraduate years in college. He is black and gay. Back in the early 1990s, as he still does today, he would often point out the differences in how we were treated by the systems that governed us, particularly in college. Though we didn't use the word *privilege* then, that is what we were often talking about. Cops would pull him over regularly in Boone and call for backup, while I only got pulled once and no back up was called. He would point out the dozens of choices I had on weekends as heterosexual male to go out to meet people to socialize and date in this small town, yet he had to drive two hours to Charlotte, N.C. to find a gay bar. I could legally marry, he could not. I could make a withdrawal from the bank without proper identification, he couldn't. At football games people assumed I was there as a fan, but would assume he was working. At a convince store a clerk would allow me to skip paying the two cents on a $1.02 purchase, but would force him to pay. Howard (2005) writes, "the manifestations of individual and institutional racism are not always blatant, overt, and easy to observe" (p. 973). But these unequal treatments still exist today when we travel together, even though he is legally married, living in a progressive West coast city, making the big bucks having worked for governmental agencies and big corporations, having earned a Master's degree, and yet, still when we are together, whether in the South or on the West coast, inevitably we run up against the same systematic oppressions as 30 years ago, only today there is much more fear involved in being shot by trigger-happy police or experiencing physical or verbal violence from angry politically-motivated people we encounter. Our similar encounters

from 30 years ago to today highlights how our identify differences and how oppressive structures and systems embedded into society still operate almost unchanged over time.

These privileges of whiteness, being male, being heterosexual feed other privileges including class and education level, and often trump others such as being atheist or experiencing disability. This plays out in my research by the very fact that my family as a white, nuclear, heterosexual family with the privilege of education and middle-class economic status allows us to stand up to our public school system in ways that others could not. And even though the final result of that stance was one of defeat, at least in changing the system, it was those very privileged identities that allowed us to make a decision to deschool into homeschooling. We had the resources not only to research the alternatives to public schooling though academic access to research at the university, but we had insider knowledge from Janet being a teacher, and the technologies to do such research including computers and internet access at home (which in our rural area at the time was not a given), and most importantly we had the time to invest in figuring out what those alternatives were and the financial capital to make it happen.

Political Context and Cultural Capital

Politically, our privilege work for us because North Carolina state law dictates a requirement of a high school diploma or equivalent to legally homeschool, an advantage many folks outside our privileged identities did not have. Politically, North Carolina is a state with few reporting requirements for homeschooling making it easier to choose to unschool, so our geographic location also privileged the choices before us. There is an

undeniable economic sacrifice to choose to homeschool, because in most cases at least one parent has to give up wage-earning in order to do the schooling. The privilege of a nuclear family with two incomes allowed us to deschool in a way that was easy and comfortable, even though there were struggles, these were in no way the barriers a single parent or low-income working family might face. In addition, the political history of homeschooling law that makes our unschooling journey possible, is built upon a political policy movement in the 1970s and 1980s to create a white space to avoid racial integration (Levy, 2009). Levy writes:

> The recent trend toward greater homeschooling participation among racially underrepresented groups seems to alleviate the perception of racism within the movement. Yet…racial integration is a significant factor in stimulating the passage of homeschooling laws. It appears that the avoidance of the multicultural experience in public schools in one possible catalyst for the evolution and growth of the movement since the 1970s. (p. 918)

As white males, both Liam and Kenyon's behavior in school was not criminalized. It's easy to imagine how Liam's defiance speaking up in class or helping others or Kenyon's incident with his pants falling down, might have resulted in school resource officers being called in or expulsion if their skin were a different color. Though Kenyon's performance on testing certainly falls under the classist and often racist (Howard, 2015) "normative beliefs that students who do perform poorly on such tests are therefore less capable, less intelligent, and inherently less prepared to do well in school and society" (p. 979), Kenyon, because of white privilege did not experience what Howard describes as "soaring suspension and expulsion rates of African American

males." The latter also applies to Liam's white privilege. Liam and Kenyon's privilege allowed them to break the rules of school that sought to constrain them, in ways that others could not, from crossing blue lines in the hallways to skipping the line in the cafeteria. The additional privilege of having their mom as a teacher in the same school, also gave our family access to information and behavior that were not available to other families. For example, staff in the school reporting to Janet about our children's treatment by teachers or the ability of Janet to leave her classroom to check on Kenyon or assist him in the bathroom.

After we deschooled privilege worked as a safety barrier, even though we often felt fear of being harassed in regards to Kenyon's experience of disability, we knew we had the resources to lawyer up, if needed. We had access to the knowledge of testing (Janet) and the resources to purchase our yearly testing requirements by the state. We had the capital to provide rich, learning environments, and experiences for our children. We had freedom of movement as a white, nuclear family to avoid questions about truancy. For our family, homeschooling and its more radical version in unschooling, were choices we could make confidently because the systems and society were set up in a way to allow us to do so with relative ease and little hassle as a white, nuclear, heterosexual, assumed to be Christian, educated, middle-class family, living in the rural South.

So my autoethnographical story comes with a caveat, it's a story that is able to be told because it is a story enabled by privilege. In revisiting the totality of the narratives from the *glimpses*, most are centered on speaking back to power, to speaking against the public school system and its agents, to wielding our unearned privilege against the system

because as white, nuclear, heterosexual, perceived Christian, able-bodied, middle class, college educated people the system would take that criticism from us and we could do it without fear of being criminalized, losing face, being deported, having the courts intervene or social workers or the Department of Social Services, and because we had the resources to hire attorneys, take off from work for meetings, and in the end had the capital both financial, cultural, and social to leave the system with little to no consequences.

Critical theory would ask, *what now?*

What Next? Social Justice Change

I turn to a *hopeful optimism* in contrast to what cultural studies scholar Lauren Berlant (2011) named a *cruel optimism*. Berlant describes this optimism as one in which a person pursues freedom without realizing the very thing you pursue is preventing you from being free. This was my family pursuing changing public schools until we realized that very pursuit was preventing us from being free. A hopeful optimism, in contrast, locates the freedom and flourishing not as an outside place one is trying to reach, but something inside the person. Though the system keeps you from fully flourishing, you can imagine a world in which all light can shine, so you strike and struggle against the machine, but at the same time allow others to see your light, so that more and more people bask in it, and join you to add their own light.

I wrote my story of light, my story of struggle, and perhaps that story and light might reach even one other person and they might join my light with their own. Holt (cited in Farenga, 1999) said this is how homeschooling would grow — one family at a

time. A hopeful optimism becomes what you create where you are and it becomes what you had hoped for in the first place. It's not an act of escape, but an act of creation. What *could be* becomes *what is*. This is the meta-purpose of my research, through an act of creation in developing autoethnography *what could be* becomes *what is* — and that mirrors the aims of social justice — that *what could be* becomes *what is*. And this research, with all its limitations, becomes one step toward creating one more possible space of liberation for those who seek such a space.

Disability Theory and Critical Disability Theory

In my research, I explored ideas and experiences of disability in various contexts from public to private, from insider to outsider, from self to other. In this exploration, I attempted to fracture expected meanings. I used disability theory to interrupt, disrupt, rupture, and break. These were not typical stories. In doing so, I often emphasized what Simplican (2017) critiqued as a "flat good/bad dichotomy" (p. 52) of disability. I lumped the folks in the classrooms, on the ground, making policy, interacting with families, writing IEPs, doing the everyday work, often paperwork, with and to people experiencing disability onto one side and those inside disability culture on the other. Simplican (2017) calls on researchers to disentangle and complicate the dichotomy of *disabled* and *abled* using feminist disability studies writing, "life-writing in feminist disability studies can solidify or destabilize the abled/disabled binary" (p. 57).

I would suggest a third way — a both/and way — a way that life-writing can both solidify and destabilize the binary without becoming a binary in and of itself. The concept of TAB, temporarily-abled body (Marks, 1996; Gerschick, 2000). It's a

pejorative typically — a term that in its use does solidify the binary diving people at the moment its used into either a part of the disability community or as outside it. But if we could reframe the term a way to include those outside the disability community as members of the community, perhaps it could be a third way to destabilize the binary. If not currently experiencing disability, all bodies are TABs (temporarily abled-bodies). If as a society we recognized that the experience of disability is something outside a body and something anybody can experience, then perhaps lines on Simplican's *battlefield* might disappear. If all people realized at any moment their own lives could transform from temporarily-able bodied to disabled, then perhaps the economic, political, and social issues people inside disability culture experience could change bringing us all closer to social justice.

While I appreciate the philosophical exercise Simplican calls for that troubles the very ground of disability theory and in particular the social model of disability, I think it works against the critical call for praxis, for real social justice change. Perhaps, in 20 or 30 years her ideas will be considered forward-looking for the time, especially if society moves toward a more socially-just world, a very big if. The fight for social justice is real, it's not simply philosophical. It's not a game. Real lives are at stake. The *battlefield* is real and it is unequal. People fighting for a more socially just world by advocating for disability rights are on the low ground of the battlefield, with few resources, small numbers, and on the other side are corporations, governmental agencies, schools, insurance companies, medical providers, all entrenched on historical high ground armed with the capital and power to hold the status quo for the foreseeable future. She

challenges the notion that "disability is always a socially desirable position" (p. 46). Entrenched in the medical model of disability locating disability within the body in ways that other and divide she writes, "[self -advocates experiencing disability] they made me feel uncomfortable in ways I failed to anticipate" (p. 57). Kudos for honest writing about her feelings, but she fails to examine the critical notion that perhaps her privilege was the source of her uncomfortableness or perhaps the historical and social systems in place that produced in her, not a relation of human connectedness with self-advocates experiencing disability, but one instead of otherness. She continues to blame the person experiencing disability asking, "how could I discuss disability rights with people who speech I could not decipher?" (p. 57). How? She could start by acknowledging their humanity and realizing that most people in this world do not speak the same language — so good researchers learn that language instead of blaming the subject for failing to live up to the researcher's expectations. She could learn sign language, she could use a graphic novel or poetry to communicate (Harrington, 2017) or art as expression or ask someone familiar with the person experiencing disability to help communicate.

Simplican puts forth the question *is disability sometimes bad?* Of course it is. My own autoethnography attests to many of these *bad* experiences. What she fails to attend to is the complicating factor at the heart of the social model of disability — it's because of the lack of supports that many of these experiences are *bad*. This is the same mistake I often made in regards to my mother's story of disability. I focused on the *bad* experiences that were the effects of her impairment of bi-polar disorder, instead of looking at the society that did not provide access to appropriate interventions, counseling, medications,

and other supports to allow the impairment to be properly addressed. If we lived in a more socially-just world with access to supports she needed, perhaps her life, and mine, would have been different. Simplican simply reduces her criticism of the social model as a "desire for disability" (p. 56). It is not that. It is a desire for a socially-just society that does not privilege the able bodied therefore oppressing the body experiencing disability. I prefer Hall's (2011) research in *Feminist Disability Studies.* Hall calls for a third way of looking at the ability/disability binary and expanding beyond the confines of those experiencing it writing:

> We need to study disability in a feminist context to direct our highly honed critical skills toward the dual scholarly tasks of unmasking and reimagining disability, not only for people with disabilities, but for everyone…understanding how disability operates as an identity category and cultural concept will enhance how we understand what it is be human, our relationships with one another, and the experience of embodiment. The constituency for feminist disability studies is all of us, not only women with disabilities: disability is the most human of experiences, touching every family and — if we live long enough — touch us all. (pp. 16-17)

Using critical disability theory as a framework, I do take a political turn and stance for social justice change in my research, as Hosking (2008) writes:

> Critical disability theory is intentionally political in that its objective is to support the transformation of society so that disabled people in all their diversity are equal participants and fully integrated into their communities. (p. 18)

This political nature of disability as it relates to public schooling and the process of deschooling is the space I explored in this autoethnography. Language being a key component of both disability and critical disability theory. Disability resides in the

system and through vivid autoethnographic stories I showed how these experience led our family to deschool in order to find more liberating space.

I believe no body is disabled. We experience disability. Disability does not reside within us. The word disability can be pejorative. It's a term used to divide society into those who wield power and those who don't. Disability theory focuses on our language and our discourse. Disability theory asks us to questions these practices. Disability theory is about power and powerlessness (Siebers, 2008). Disability theory is about radically re-imagining the very meaning of disability. Disability theory embraces contradiction, polysemy, multiplicity, complexity and chaos. This is where I do agree with Simplican. At the same time we must as scholars describe disability, we must resist monolithic categories. The experience of disability is variant and contextual and there is much disagreement. However, if a socially just world is our goal I believe we have to reimagine the disability experience not as *other*, as *abnormal*, as something to be cured, prevented, or rehabilitated. We do have to take a stand and imagine disability as beautiful.

Disability theory is about social justice change (Mladenov, 2016). I do not believe Simplican's arguments or her conclusion, which reduces a serious topic to an online quiz as a serious analysis, it simply lacks the *critical punch* she seeks to describe. I do believe this autoethnography of deschooling from compulsory public schools into homeschooling can be a rupture for those with the open mind and imagination to envision a new way of being in the world. And the *critical punch* is in the alternative site of liberation it suggests as a space for just education.

Harrington (2017) describes a concept that also describes my autoethongraphic story of unschooling as a place of *interdependence*. She writes:

> Independence has long been promoted as the absolute ideal for people with ID [intellectual disabilities], underscoring beliefs that reaching some "normalized" state of autonomy is what allows for inclusion into the community. Like black feminist scholars however, I think that recognizing the importance of interdependence is a better hallmark for inclusive communities…one could argue that interdependence, rather than independence is at the heart of inclusion, because it requires that involved parties find mutual value in one another. (p. 176)

Harrington's description of interdependence not only describes our unschooling experience, but our life experience, though as Illich (1971) would remind us there is no difference between the two. Though public schooling became an exercise in seeking inclusion that resulted in exclusion, it was through deschooling into unschooling we found a new place for a *interdependent* inclusion, ironically by excluding ourselves from public schools. This highlights the significance of this research. It opens up new possibilities for families with children who experience disability to enact their own unschooling paths. If more and more people take this path, it could become more well known as a possible space of liberation, of just education for others. We need this new idea, especially for people experiencing disability, as Grigal and Hart (2010) write:

> New ideas will indeed be necessary to complete the social revolution for people with disabilities that began in the 20th century…data reveal that 90% of adults with intellectual disabilities were not employed; fewer than 15% participated in postsecondary education; and over 700,000 people with intellectual disabilities lived with parents aged 60 or over. (p. xi)

The researchers point to the interdependent reality for people experiencing disability, and in particular intellectual disability. Kenyon will likely live with us as long as we live. After we die, he will likely live with Liam. Our unschooling journey is one that does not end when Kenyon officially graduates next summer. It will be important to continue to story our journey, to forefront new ideas for unschooling and living interdependently, and continually searching for new spaces for just education.

Reflexivity

Berry (2013) offers a set of reflexive *selves* for autoethnographers to employ in creating a critically-oriented analysis of the the textual products created writing:

> Doing so in ways that put experiences, that put us, on the line, as voices who use critical cultural scholarship to advocate for justice — renders doing reflexivity well essential. Part of this means appreciating how reflexive inquiry provides more intimate and informed inquiry and how the selves explored autoethnographically, like discourse generally, are always and already situated, contingent, fluid and often contradictory. (p. 221)

Berry (2013) calls our attention as critical autoethnographers to address our historical selves reflecting not only on the production of our histories in the autoethnography, but what the end result on our self is, "whether this work enables selves about which we feel happy and/or distressed…" (p. 222). Addressing the latter, I feel both happy and distressed about the historical selves I produced in the autoethnography and the self of today as I write. I feel a pride of having researched and written a text that holds potential for social justice action by the people who read it. I also feel distressed about many of the vulnerable, personal details I reveal about my life, such as my personal

struggles with spelling and my family history with mental illness, both of which could be used as weapons against me professionally. Flemons and Green (2002) echo these concerns:

> When you write a story of yourself, you accept an assumption about yourself that then determines in part how you understand yourself, and if you publish this account, then you are defining yourself not only personally but also professionally. (p. 90)

I know the temporal nature of the autoethnographic texts I created. I am not who I was 10 years ago and 10 years from now I will not be the same person represented in this text. But will a reader know this? The same applies to the production, not only of my own historical account, but this record of our family's deschooling account, of Janet's story, and Liam and Kenyon, too. Though I clearly dictate the tentative nature of storying life, especially when it intersects with others, and make no claims of universal truth, the story can be read by others as universalistic. Analyzing the historical selves produced naturally leads into Berry's second reflexive lens — the *processing selves*.

Berry asks us to examine the process with an emphasis on what was chosen to be told and what was left out. It is important to recognize that no one's entire story can fit onto the pages of even the longest research project. The autoethnography is short of the full unfolding of our journey. Even so, I believe the work represents a story of voices that are typically silenced in the public school system. Most of the stories told in education literature focus on the stories of schools, teachers, administrators, and when the researcher turns a gaze toward the student or family to tell a story — those stories

typically represent an outsider perspective with conclusions focused on improving the public school system or improving the *fit* of the family into the existing system. While growth in scholarship on homeschooling and unschooling continues as more and more families opt out of public schooling, the amount of scholarship pales in comparison to research focused on public schools.

The story I wanted to tell was not the objective story of an impartial researcher who hopes to shed academic light onto the difficulties of inclusion/exclusion in public schools in hopes of bettering the schooling process for future families by providing teachers/administrators and families insight into the process. The story I wanted to tell is the localized story of our discovery of what Berlant (2012) calls a *cruel optimism* — for us a blind faith and optimism in the goodness and rightness of public schooling shattered once we discovered the hegemony imbedded in the fact that our own pursuit of our desire for inclusion prevented us and our children, Liam and Kenyon, from flourishing. I believe this research shows not only the cruel optimism of trying to change public schools, but a hopeful optimism in the discovering of an alternative path — unschooling.

As for what was left out of the story. I cut much of what I wrote about race and gender. As my writing grew to more than 500 pages, I realized much of my narrative would not make it into the final product. I focused on stories related to disability and schooling. This meant that many stories of the intersectionality of my identity were left out. It also meant cutting out a key component I thought would add to the story, but room didn't allow — the economic story. In short, there is an economic side to homeschooling and in particular to my story. This absence of the story of being a contingent adjunct and

lecturer at a university, living on year-to-year contracts, combined with the pressures of typically living on one income, is notably a weakness of the autoethnography. I think most families who live the homeschooling experience would note that how to make ends meet is a serious part of the story. Related to the economic story is the story of privilege and white privilege in particular.

While I do address privilege in several brief passages, it is more of an afterthought than focus. There is some argument from homeschooling/unschooling scholars on the role of white privilege. Donna Nichols-White (1996) writes an essay in Hern's book *Deschooling Our Lives* that positions as myth "that deschooling or homeschooling is only available to middle- and upper-class white families" (p. 72). Hern's 2008 volume that expands his 1996 version leaves Nichols-White essay out and Hern addresses white privilege writing:

> Because these writings represent a radical reimagining of our society. And if that's what we are after—and I'm arguing that it has to be—then deschooling can't be just another lifestyle option for the most privileged people in world history. We have to take common responsibility for making alternatives to compulsory schooling commonly available—otherwise deschooling just becomes another brick in the wall of white privilege. (p. 116)

The autoethnography would benefit from further analysis of the role whiteness and privilege played in our family's ability to deschool/homeschool/unschool. In addition, more attention to other privileging identities such as heterosexuality, education level, and class, and how these identities intersect, not only in our family, but in the families that are deschooling in our county. Before we deschooled, we were always

shocked when other families pulled their children from our local elementary school. Where were they going? We don't have private schools here. Most left for homeschooling. We asked why these families — who supported the school, supported the PTSA, volunteered — why are these parents pulling their kids out of school? Each had their own story that ended with the self-justification of making the best choice for their child. Another thing most of these families had in common is privilege and whiteness. Most had not only the financial capital, but the social and culture capital to navigate an exit from schools into something else at home and the means to support it, even if it meant one parent leaving work to stay at home.

Another reflexive consideration of what was left out involves thoughts and writing that run counter to the narrative. I cut the following passage, but add it here. My historical and processing selves say there is guilt that comes from thinking or having thought what is now something you consider unthinkable:

> During my graduate study, it was a rare experience to come across an article in any of my classes that mentioned Down syndrome. My youngest son, Kenyon, experiences Down syndrome. Rhetorically, I frame this as he *experiences,* not he *has* Down syndrome. Too often, scholars reify the notion that disability is something *real* located within a person. Disability is not located inside my son, it is located in the *society* that surrounds him. For example, disability does not reside in the user of a wheel chair, even though our society would imply it does. The disability resides within the building that was not constructed without wide doors or an access ramp. The disability resides within a society that embraces a medical model of disability (Siebers, 2008) of one normal way of being in the world. Kenyon experiences Down syndrome, but that is only one aspect of who he is. DeGrazia (2005) writes of enhancement technologies imagining what, if any, impact there would be if gene therapy could be applied to someone who experiences Down syndrome. The question resonates with me because it is something I have selfishly thought about. Or I used to, especially right after Kenyon's birth. And also because it is one of the most common questions I get

> asked — *if a drug or therapy came along to remove the extra chromosome from each of his cells, would we do it?* Yes, I'm serious. I usually get asked that by people I know, who have gotten comfortable enough to ask it. The assumption is that Kenyon is *broken* and the drug or therapy would *fix* him. And I once thought that way, too. I dreamed of what his life would be like if he just didn't experience Down syndrome. It was an easy dream to dream when he was a baby. But as his identity emerged through his personal narrative, through his biology, through a combination of all that he is and all that he experiences, you begin to see that Kenyon is a valid human being, living a valid way of being in the world, and that he does not need to be fixed and is not broken. I've interviewed a lot of people who experience a wide range of disabilities and many report frequently being asked questions similar to the one DeGrazia proposes — that if an enhancement could *get rid of* your difference, would you do it? To me it says more about society that poses the question and how posing the question reifies the notion of *normal* that drives the very concept of a medical model of disability or images of the broken other. The fact these ablest ideas not only occurred to me, but became, if even for a moment *thinkable*, shows the power of binary, dichotomous notions of identity that run rampant in our society forcing us into boxes.

Berry's reflexivity involves identifying our *breaching selves* or a call "to deliberately perform in ways that contrast with (that is, breach) social custom." Berry calls for breaches including performances that disrupt the status quo and draw attention to social justice. If processing selves is a weakness of the research, then breaching is a strength. In choosing to exclude our children from public school, we were rejecting the inclusion/exclusion binary by choosing a third way, a breach of typical expectations. We hoped to transform the school by shocking the school. It's not often a teacher at a school chooses to send her kids into another educational setting. Yet, that was what we were choosing to do.

I think it was a shock at first. But quickly the school, the teachers, administrators, fell back into the daily grind of life inside the system. They forgot or moved on and continued the status quo. I don't think we have made life any easier for any other

families. But maybe we caused someone to pause and reflect on the school system. Perhaps Janet's colleagues questioned their own schooling choices made about the children they served. Others may have been glad to see us go. I'm sure life at school became easier without us. The shock of us pulling our kids out of school was not quite the shock we thought it would be to the system. Just like we failed to trail-blaze a new path, the multi-headed hydra of public schooling continues keeping its educational industrial-complex funded by keeping the current power structures in place. However, maybe I'm underestimating our impact.

Since leaving, we have had parent after parent tell us that they wish they had the resources to homeschool. More and more teachers share stories with us about their own frustrations with a system that will not change. Many say they are just hanging on, waiting until they can exit the system. By building our own homeschool/unschool and encouraging others to do the same, perhaps we are participating in a revolution. Maybe this is our new path. The public system is so broken, we feel we cannot make any effective change. We know we will not subject our children to public schools again. By storying this experience, perhaps others can find a third way.

I merge Berry's *contested selves*, that calls autoethnographers to reflexively examine their social justice praxis and stand against injustice and exclusion, and Berry's *unapologetic selves* that asks the autoethnographer to embody a "sense of assuredness, or, at the very least, a confident spirit in foregrounding researchers' selves" (p. 223). My contested selves cry out for social justice, or at least what I saw as exclusion and injustice.

Inclusion sounds great, but is it? Kenyon's life in school would be a constant battle for our family to ensure the supports he needs are in place. Why would we want to spend all of our efforts and time fighting for these supports, when we can provide those at home? And in providing those supports at home, we have more time left to take the supports to a higher level. Why would we want to include Kenyon in a school where he is likely to experience abuse and bullying and neglect? We saw in kindergarten he was a victim of violence from other students.

The same goes for Liam — turning him into a test taking robot, zapping any critical thinking skills, initiating him into a gendered, sexist, racist culture that did not reflect the values of our family, or the values of social justice. Immersing him in a culture that celebrates violence, war, blind obedience to patriotism, patriarchy, hierarchy — that is no way to live for any student, much less our own kids. There was no way to leave our kids in school once we came to these realizations. To leave them there would be immoral. Pulling out of public schools was not just about excluding ourselves from the school system but including ourselves in something greater. I see a bumper sticker around town a lot: *If you're not angry, you're not paying attention*. We have a lot to be angry about. But that is no way to live life.

A better bumper sticker I saw once: *bark less, wag more*. It's not that you can't be angry, but you can't live your life in constant anger. Especially the years when your children are growing up. This precious time can never be regained. Why waste our children's lives by forcing them into a system where they will be abused, bullied, neglected, and all for the small hope that by including them there, the system will

change? That would be unfair and unjust to the children. If you see a child suffering, and don't do anything about it, what does that say? I had the power to end this suffering for our children, by excluding them from school. I know it was a decision we could only make because of the white privilege that made it possible.

I realize the possible social justice contradiction that because we experience privilege we should be the ones staying in school to transform it. But I don't buy that. There is more than one way to transform society and when you realize you are beating your head against a rock, you better realize quick the rock isn't the one being hurt. It doesn't mean our efforts to transform public schools stop. But if we never change public schools for the better, at least we know we've saved two children. And by storying our journey, perhaps others will be encouraged to follow our example (Alexander, 2013). If enough do, maybe the system will be shocked into change or maybe no one will be left and society will finally be deschooled. Wag! Mine is a story of healing and a story that heals. In the act of writing and telling the story, a catharsis takes place that helps us move on and may help others to understand their own personal journey (Alexander, 2013) out of public schooling.

Though I believe I took a bold unapologetic stance that Berry calls for, could I take it to a higher level? Could I create a hyper-unapologetic self that also is a way to reflexively examine Berry's final aspect of *hopeful selves*? Berry (2013) calls hope messy writing "hopeful autoethnographies, rarely occur without ambiguity, contradictions, and complications" (p. 223). Berry challenges the researcher to "become risk takers and take chances; who we wish to become is worth any fallout that might occur through our

becoming." With that, I offer a reflexive imagining of an email exchange where I take the section of my dissertation regarding disability theory and modify it for a fellow graduate student.

Please, Hold My Beer While I Respond

Hey there.

Thanks for writing to me.

So, you want to interview special education teachers to ask how their teacher preparation programs prepared them to teach both a functional and academic curriculum to students with severe disabilities? And you want to focus on evidence-based research?

And you want my honest thoughts on how disability theory plays into this as framework? Ok, sure.

For what it's worth, here are my thoughts. Let's lump all special education service providers from teachers to therapists to counselors all into an easy to type acronym (SES).

The question is phrased in a way that is anti-disability theory. It is asking SES folks how they act upon those labeled as abnormal or who experience *severe disabilities*, so that those disabled bodies and minds might fit better into the able-bodied world, and better yet, let's make sure we can quantify the results of the research as evidence-based, so we know that we are oppressing, oops, helping those pitiful folks experiencing disability.

My question, from a disability theory perspective, is why are you focusing on what teachers DO TO the OTHERS? Are you OTHERING them yourself with your research? Are you reifying the notion of disability? Whose social values are you researching, the status quo, the able-bodied, the *normal*?

Think about it, you are asking able-bodied people what they should learn so that they can more efficiently, and in an evidenced-based way, force people experiencing disability into a more *normal* way of being by providing a functional and academic curriculum.

Disability theory would ask, what about agency? What about advocacy? What about a curriculum focused on teaching agency and advocacy to these students? Disability theory would say, "quit labeling me" as *severely disabled* and instead focus on my humanity. Call me a student.

Disability theory would ask you where are YOU locating the DISABILITY? Do you locate it in the person? Is a person disabled? Does the disability reside in the person, severely? NO! Disability resides in the system. A person who uses a mobility (wheel) chair is not disabled, the disability is not in her legs, her body, her DNA. The disability is in the building with no ramp. The disability is in the room with narrow doors. The disability is in the temporarily-able bodied people who force her to accept a label to get an accommodation. The disability is NOT in the person, but in the social constructions society creates that oppresses the person who experiences disability.

NO BODY is disabled. We EXPERIENCE disability. IT DOES NOT reside within us. It's a pejorative. It's a term used to divide society into those who wield power and those who don't.

Disability theory focuses on our language and our discourse. SES schools teachers into accepting a disempowering language that reifies normalcy. There is no normal except that which keeps the status quo in place. The language of SES works to keep those with *severe disabilities* hidden away in their own schools, in their own classrooms, with their own teachers, with their own bathrooms, with their own tables in the cafeteria, with their own peers, with their own *special* curriculum.

Disability says FUCK THAT. Yes, it does. Disability theory likes to cuss. Disability theory likes to interrupt what is expected. Disability theory likes to make folks uncomfortable. And it makes NO APOLOGIES for it. Disability theory says tear down those walls. Shred the folders. End the labels. Disability theory says ALL STUDENTS belong together under one roof, in one classroom, on one bus, with one teacher. Yet, SES continues to segregate students experiencing disability. Can you imagine a school asking to put all the women in one classroom and educate them separately, or all the folks with one skin color, or all the folks with one income level or all the folks who aren't heterosexual, or all the folks who don't speak English...ok, wait, they do that sometimes, right…but see the point? Students experiencing disability are typically the only ones segregated into separate classrooms and separate schools, and why? For their own good?

NO. For the able-bodied, for the normal kids, who can't be held back or forced to interact with, or forced to look at, for forced to learn sign language or forced to learn another language.

Disability theory is about power and powerlessness. Does what pre-service teachers in SES are taught work to empower their students or just control them, or just prepare them for the job that awaits them in food or filth? Yes, students experiencing developmental disability, if they are lucky enough to find work, can look forward to a life of work in FOOD or FILTH. Are functional curriculums just training them as food and filth workers? Could they aspire to something more? Why not the arts? Why not anything else? Because students experiencing disability don't fit the *normal* standard of the able-body majority, and they are forced in roles of service or relegated to the margins of society. So does the functional curriculum teach agency, advocacy, resistance? Can you tear down the house with the master's tools? NO.

Disability theory is about radically re-imagining the very meaning of disability. This strikes at the heart of SES teachers. SES is about fitting into nice little boxes, so that all the paperwork is correct and no one loses funding or worse, no one is sued. Disability theory says teach me how to stand up for myself, how to create spaces for me to change my own life, to open spaces for me to do something not expected, for you to ask me what I want, to be free of a functional or academic curriculum that is not of my own choosing, for me to educated alongside ALL the other students instead of hidden away. Disability embraces contradiction, polysemy, multiplicity, complexity and chaos.

Is disability beautiful? When you see a person who experiences disability, can you imagine them as beautiful? Disability theory asks us to stop seeing those who experience disability as the *other*, as *abnormal*, as something to be cured, prevented, or rehabilitated. Is your work in SES about returning a person to normal? Is your work about establishing some quantitative idea of a *normal* and changing this student into it? Are you changing or supporting? Shouldn't SES be about supporting students in their self-directed learning? Should all education be about that?

Is disability beautiful? I think so. Some people see pity. Some people see disfiguration. Some people can't see beyond the limits of their own stereotyping and oppressive behavior. Think about it. All rights movements go through a phase of having to declare themselves beautiful. The civil rights movement did — black is beautiful was the mantra. The gay rights movement did. Now, the disability rights movement is doing the same thing. Disability is beautiful. Don't change me. Support me. Love me. Respect me.

Disability theory is about social justice change. The bottom line is to ask yourself — is your research just a way to ensure the status quo of SES continues? Or is it a way to rupture what is expected and change the world?

The same is true for you and for me and for anyone reading these words. What are you doing in your life that ruptures the status quo?

Comparative Evaluation with Liam's Own Narrative

Unbeknownst to us a writer contacted Liam via email to ask him to write a few essays for her book. He didn't mention it to us. I guess there was no real reason to tell us.

He certainly didn't need our permission. And we were all so busy with the band, medical issues, work, graduate school, and all the daily living that seems overwhelming at times. I often wonder how folks have time to go to public school? We don't have the burden of compulsory school, yet barely have time to get everything done! Nevertheless, about a year later the author sent us a copy of the book. Liam's words speak more to our unschooling experience than perhaps anything I've written during my research.

In evaluating autoethnography Witken (2014) suggests comparing narratives "in relation to other narratives" (p. 15). Using Liam's narrative as a comparison serves as a useful and reflexive means to look back on my own narrative, especially considering I didn't have the chance to read Liam's essays until after the vast majority of my narrative had been completed.

One of the first differences I noticed is that Liam attributes his accomplishments to his own hard work, whereas I often attributed his accomplishments to the method of his schooling or rather his unschooling. I'm not the only one. As Liam points out, much of society tries to attribute his success to geography to the water supply to anything except the actual hard work of a child. Liam (as cited in Lawson, 2019) writes:

> As someone who has been a multi-instrumental musician since I was little, I've heard a lot of people talk about the talent I must have been born or blessed with. I would be rich if I had a dollar for every time someone has said to me; "You're from Deep Gap? There must be something in the water up there!" Although it's a popular belief that great musicians possess something that others do not, in reality the only special assets they have are passion and dedication. (p. 46)

Liam writes passionately about his work ethic, something I did not address in my autoethnography. In Liam's account he is a subject with agency. In my account, both he and Kenyon are often objects of the actions of the various characters in the public schooling story or objects of decisions made by parents. Either way, I certainly did not give enough credit to either Liam or Kenyon for their own agency. One place I did succeed in this was the writing of Kenyon's crocodile dance story. In this instance, I did write about his concrete actions of refusing the help of others to make his own way. Liam too, has agency and his writing shows that fact:

> Folks often overlook those two [passion and dedication] qualities, instead attributing someone's musical greatness to "talent" which in this setting is just another word for "luck of the draw." This is especially true for young kids who get into music early on. Crowds aren't used to seeing a child with the amount of work ethic necessary to master an instrument at a young age, and often overlook the hard work that young person has put into their craft. (p. 46)

In my autoethnographic account, I don't give enough credit to either Liam or Kenyon for their own intrinsic motivation to learn. While I did write about the music community around Liam, I did not, as Liam did, point to the importance of community to the learning process. I tended to focus on individual aspects of Liam and Kenyon's life, rather than the greater social life around them. Liam points to these important influences writing about music and sports:

> Here's a little bit about how I view passion and dedication as the keys to my musical accomplishments. Passion, or perhaps motivation would be a better word, is the first step in the cycle for me. In the beginning it came from my attraction to bluegrass and old-time music, and now it comes from countless places. My motivation to improve, expand, and create is the fuel I need to get through the

> work involved with achieving each of those goals. It keeps me going to have other musicians to look up to, or friends who are musicians to compete with. Much like sports, there can be no improvement without motivation, the passion necessary to succeed. (p. 46)

In my narrative, I cover a wide time range of 13 years. In choosing what to write and what to leave out, I believe I did not include enough stories about not only the amount of time Liam and Kenyon put into learning, but the types of learning work they did. I tended to focus on their accomplishments, such as Kenyon's mastering of the Wii controller or winning ribbons, or Liam's musical accomplishments, rather than the process. Liam, in his writing, instead of boasting about what he has done, humbly admits he is not complete, writing:

> Next comes the dedication, code word for a lot of hard work. Musicians, like all artists, put in an incredible amount of time to become proficient, and then a staggering amount of time to become masterful. I see a lot of musicians (especially the young ones) take the time to become proficient at a handful of songs and go no further, which is okay; but what the audience doesn't know is how much hard work it takes to be considered a well-rounded, masterful musician (something I'm still a long ways off from achieving.) Time is certainly the catalyst to hard work. I was home schooled from the 3rd grade until Fall 2018 when I enrolled at Wilkes Community College. That and the fact that my parents basically gave me the wheel in regards to my education, meant that I was able to spend a ton of time learning and perfecting my craft. I have been playing for around 10 years now and put in many hours a day (around 4-5 lately) seven days a week. (p. 47)

While I do write about Liam as a teacher, I perhaps do not focus on that aspect of his life enough. Reading his account of his experience unschooling makes me realize that even in his writing he is teaching:

> People often get frustrated with their skill level in relation to the amount of time they've been playing, which is usually a function of only playing music for a few hours a week, or less. Everyone's goals are different, and not everyone needs to play at a professional level, but there are no shortcuts to learning music, and time is a big factor in mastering an instrument. All of this to say; when someone assumes where my musical ability came from, a musical family, God, random instinctual talent, or something in the Deep Gap water supply, I'll usually agree and wish them a good day. But as those who have asked me know, and now you do too, the musical tendencies and proficiencies I possess and continue to develop, are born of a love for all kinds of music, a lot of time, and a lot of hard work. (p. 47)

While I don't give enough credit in my autoethnographic narrative to both Liam and Kenyon for the active role they play in their own learning in our unschooling life, Liam does give credit where credit is due, and perhaps more credit than is deserved:

> People may just see a professional band as the people making music on the stage. In reality, there are equally important people working behind the scenes to make the show possible. For Cane Mill Road, those people are our family. My parents supported me and my music from the outset. They drove me to about a million different festivals, workshops, and concerts. When the band first started, my dad helped with the booking. My mom home-schooled me so that I could spend more time practicing. As we became bigger and started touring, my dad became our official manager. My mom was in charge of our merchandise and cooked for seven on the road. I can honestly say that without my parent's support, I would be nowhere near where I am today. Thanks to my dad's booking skills, we were the first band in our age range to start touring nationally. You can find a million talented kids, but you see very few teens who already have a successful career. The difference is the wonderful support of a family. (p. 48)

Also in the book was a transcript of an interview the writer conducted with Liam in 2016 during a photo shoot at Reed Creek Farm. While I drove Liam there, I was not privy to the interview, as I was in the car working with my laptop and cell phone trying to earn that greenback dollar to keep this whole unschooling enterprise going. I had really

forgotten that the writer interviewed Liam until I read his words in the book. This account occurred three years earlier than Liam's writings above. This transcript, reprinted in the book, were of an interview when Liam was age 13.

Liam's narrative account summarizing how he learned music mirrors my own narrative from the autoethnography. I include it here just to allow space for Liam's (as cited in Lawson, 2019) story in his own words:

> I grew up hearing bluegrass and old-time music all of my life. I live in Deep Gap, where Doc Watson is from, which was always a big part of the community. When I was about 6, my Dad asked me if I would like to take music lessons from his friend, Mark Freed. So, I started taking guitar lessons every Thursday. After a year went by and it was time to enroll again, Dad asked me if I wanted to continue. So, I said yes, but I wanted to try and play the fiddle, and so I took fiddle lessons until I was nine. By then I had also picked up the banjo and mandolin. After a while I sort of 'graduated' from the JAM program and I started teaching there, as an assistant. I was actually not very good at first, I mean, it didn't come very easy to me. It took many years for me to improve, especially with the fiddle. I played old time for many years, which I know might may not sound long, coming from a 13-year-old! Ha! But about three years ago I started getting more interested in bluegrass. So, I started a bluegrass band named Cane Mill Road with some friends and I think it really brought us a lot closer. (p. 61)

Liam's narrative of our decision to unschool takes more credit for the decision than I gave him in my account. My autoethnography focused on our power as parents and reified the same sort of authoritative power that I was critiquing in the public schools. A pattern throughout this comparison of narratives is the lack of credit to Liam for his own agency on my part. Liam aptly describes his own unschooled life:

> I am home schooled. I went to public school until 3rd grade. I have a little brother, Kenyon, who has Down syndrome. When he was in Kindergarten my parents decided it would be best for him to be home schooled and so I asked if I

> could be too. So, that Christmas we both stayed home and have been home schooled ever since. It really gives me so much more freedom! It's so much easier to schedule things and music class can last as long as I want it to! I work do work on regular stuff, such as math and Science and such, but it's really been all about what we want to do! I was the 2014 winner of the Brian Friesen award, which is a memory of Brian, he was a banjo player. His parents started this award with Deering Banjo. So, that is how I acquired my banjo. It wasn't my first, but it's definitely my best one! I have taken first place mandolin in the youth division and I won the Fiddler Grove Hot Licks competition. I was taught to play by ear so I would learn to play a new song every week. I feel like 'playing by ear' gives you a lot more understanding of the music. A lot of people say they like the sound of music that is played 'by ear' rather than by sheet music. It's a different more natural sound. (p. 61)

I notice in Liam's narrative he doesn't include his grandma Cathy, while she is a major focus of mine. Perhaps that is because she was a major focus of my life and not of his. In fact, we tried to shield both Liam and Kenyon from the chaos of her life, but I still believe he was aware of more of that chaos than I realized, as on the day he asked me why the police came to our house to ask about Grandma Cathy. Liam writes:

> My Grandparents live on the coast and none of them play music, but I have my great-great Grandfathers' fiddle. It's an old factory fiddle. Both of my parents and my little Brother have been very supportive of my music, every step of the way. They are great! They take me to all the conventions and spend a lot of time with me. (p. 61)

Liam describes, in two short lines, the essence of our family's lives and purpose. Something that takes me hundreds of pages to try to convey. Perhaps, I needed to write those hundreds of pages in order to come to this conclusion. But Liam seems to realize it

much easier than I do. Our unschooling journey is about time together. Liam writes, "it has always been the focus of our family, to be together. It's the four of us and our dog" (p. 61).

Reading Liam's interpretation of growing up as the brother of child who experiences a disability, made me realize that perhaps I didn't pay enough attention in my narrative to the effects of the relationship on Liam. While I do mention how involved Liam is in Kenyon's care and learning and everyday living, I give little attention to the interplay between them or how Liam might perceive disability differently than I do. It's interesting to note how Liam characterizes Kenyon's loss of walking ability by saying "he used to love to dance." I don't address Kenyon's thoughts about his own loss of one of the most important aspects of his life and this is another hole in my narrative that Liam is able to bring forth with his own writing in comparison:

> Growing up with my brother is the same as any other brother. I just love him to death! It hasn't been a hardship, but it's a different experience to grow up with a brother who has to face all the struggles that he has. However, our family really loves him. He loves to be hugged if you want to give him one! He hasn't taken to any instrument other than percussion. He used to love to dance and he will sometimes play the tambourine. (p. 61)

Toward the end of my autoethnography I write about prophecy. It was partly a literary choice to contrast our anti-religious views, our economic status, and education levels with the folks who might not share the same and to show that even as self-professed agnostic atheist-leaning progressives, we don't always measure up to the labels. In much of my writing, I try to show how life can rupture what you once held as

solid beliefs. Liam shows that too, in his writing. One of the most common questions he gets, other than what's your favorite instrument (a question he refuses to answer, because he says he loves them all), is will you go to college, where, and what will you study there? I guess that's three questions, but they all get to the same point. Liam is comfortable with the ambiguity of the future, much more than I am. And he is certainly more hopeful in his writing than I am in mine. Liam writes:

> There are so many great folks in the bluegrass business and I just hope to be one of them someday. I don't know yet if I will go to college. I would love to support myself with my music. If that turns out to be possible. I know that my parents are very supportive of my following my dreams. I wouldn't mind doing other things in the music field, such as recording or engineering. I have self-produced a few CD's on Garage Band. Our band did just finish recording a CD, so we will be selling that this year. I love playing all the different instruments. I feel like they complement one another and it helps to see how they relate. It's kind of like all the different roads that merge onto the same highway. I just know I want to stay on this road that I am now on and keep on going to wherever it leads me! (p. 61)

Liam's narratives add to our family's story of unschooling in a way that my own stories do not. I am constrained by my own bias as a parent, he is not. I am constrained by the requirements of academic writing, he is not.

As I articulated the impact I hoped my research might have I always thought of other families with children who experience disability. I thought of policy makers and politicians, service providers and teachers, medical professionals and principals who might read the work and experience some sort of transformation that might help make public schooling better for those experiencing disability and their families. I never thought about how my ideas or our family's unschooling experience might impact Liam.

The biggest part of our living and learning experience as unschoolers is simply that — living and learning as we go through life together. We talk. We do the things of life both mundane and extraordinary. We discuss. We remember. We fight. We celebrate. We cry. We simply love each other as we live our lives day to day and we end up learning along the way. I think our family is a good example of Illich's (1971) utopian dream of a life of leisure where learning happens naturally as a way of simply living one's life in respect and honor of the people around us. But Liam's words make the abstract real. He has learned much more than I have. He is a much better person than I am. He is a better teacher. But that is how it is supposed to be, right? It's every parent's dream that their children will do better in some way. To me, Liam's words are the only validity I need. I can't know how my research will change the world, but I do know what Liam thinks, at least at the moment he wrote these words. This is validity to me. This is change. This is hope.

CHAPTER VI

FINDINGS

When I first thought about my dissertation, I thought I would study the growth of college programs for students who experience developmental disability. The further into my research, the more I questioned my focus. Initially, I never questioned the program I intended to study. How could anything be wrong that opened the doors of college to kids like my son Kenyon, who experiences disability as Down syndrome? However, my family's personal story of Kenyon and his inclusion and exclusion in public school came to a climax just before starting my comprehensive exams. Kenyon's tumultuous first year of kindergarten resulted in our family abandoning public schools for homeschooling. This was not a casual decision. This decision ripped apart our identities as educators, as progressives, and as parents.

After decades of defending, supporting, and working for the idea of the public good through public schooling, after the false-belief that being insiders in the public school system would make a difference, and after the naive notion that *we* would be trailblazers of social justice pioneering a new way, a new wave of inclusive education — we gave up on changing the direction of the public school juggernaut.

Our voices were silenced, our children were harmed, and the years of goodwill and foundation building in preparation for Kenyon's inclusion in public school were thrown under the bus. We fled the inclusion/exclusion binary trap of public schooling. In

leaving, and in a search for healing, we found a world of others who had also been silenced, harmed, and had escaped. There were also supportive others who never entered the system, so only know it through the stories like ours.

Our experience in public schools not only left us in a crisis of identity, but left me questioning the subject of my dissertation. If the public school system could not make a safe space for Kenyon, how could a college program? If the public school system viewed Kenyon as a commodity for special education funding, how would extending his education to college be any different? If students experiencing disability are used as public relations props in public schools, could it be that universities were doing the same? Do universities create programs for students with developmental disabilities because they want to transform society, or because of the positive public relations exposure gained from such inclusion? Are these programs truly in the best interest of the students served or does it become a warm and fuzzy way to create human lab rats for faculty and for so-called *typical* college students who take classes alongside these students? In researching this program, was I becoming the privileged researcher using the students in the program for my own personal gain? These were cynical questions. These were critical questions. These were not the only issues affecting my choice of research subject for my research, but these were the questions that pointed me toward the need to story our family's journey as a radical alternative to the public schooling paths in both elementary and post-secondary institutions that I had been considering researching.

Too often, education scholars focus on a monolithic image of public schooling as the only site of education. Sure, sometimes they might throw in a nod to higher education

or even birth to kindergarten or even a wink at continuing education programs. I feel it is time to seriously consider Illich's (1971) notion of abandoning public schools as an option. If we shouldn't deschool our society, shouldn't some of us at least deschool our lives? Should education researchers turn a scholarly eye to the growing worlds of homeschooling and unschooling that may be a truer harbinger of the future of schooling in the United States, truer than looking within public schools?

I told one localized story of what happened to one family as an autoethnographic account of inclusion and exclusion in public schools and in life, as we deschooled, homeschooled, and unschooled. The messy, fractured, layered, complex, chaotic, tangled tales of our journey out of public schooling into something new is a critical, interpretive, literary, and performative autoethnography that I hope will serve others interested in pursuing a similar journey.

Rousseau and Dewey

Our version of homeschooling in unschooling is grounded in concepts popularized by French philosopher Jean-Jacques Rousseau more than two centuries ago. Spring (2008) writes, "Rousseau believes that the child is born good and the greatest dance in childhood is corruption by the outside world" (p. 39). While we, as parents, did believe that children were inherently born *good*, we did not necessarily believe, like Rousseau, that the outside world was responsible for corruption. Though we did arrange our lives so that one parent could stay at home during the early years, it wasn't to protect against a corrupt world, but instead focused on the love, attention, and resources we could provide at home, compared to the daycare options available to us in our rural

community, which were substandard at best in our eyes. However, that attitude changed once our children were attending our local public school.

My autoethnography is a story of the realization of Rousseau's theory that perhaps we do need to protect our children from the outside world, or in our case, the inside world of public schools. I wrote about how we limited our children's access to media and the Internet, and news, and how public school interrupted that access because peers were providing messages of prejudice, hate, gender bias, stereotypes, and violence that we sought to avoid at home. Though we didn't go as far as Rousseau and his protagonist in his book *Emile*, in which Rousseau writes about isolating the child from society, we did mirror other aspects of Rousseau's philosophy. In regards to isolation, our children experienced more socialization than perhaps their public school peers, because we sought out a broad range of social interactions that came through every day living, not just with same-age peers, but with all ages and with as many different personal and cultural identities as possible.

We did enact Rousseau's *negative education* which Spring (2008) describes as "learning is to be a product of experience, not moral and verbal instruction" (p. 40). This ran counter to the emphasis of memorization and obedience we felt were a major part of the public schooling curriculum. Our unschooling adventures in creeks, lakes, mountain trails, gardens, greenways, bike trails, mountain roads, fiddle festivals, old country stores, and countless other activities of daily life from grocery shopping to banking to paying bills to yard work to household chores — all these experiences were part of the learning process and part of our daily living with no separation between the two. Where we

differed with Rousseau is that we did engage in moral issues, reading, and verbal instruction with our children, rather than wait for Rousseau's appropriate age of adolescence (Spring, 2008) to engage in these topics. Part of this is because life forces moral conversations into lives, especially when a family experiences disability. You can't ignore a child's questions about many of the topics I wrote about in this research from police knocking on our door late at night to visits to death to discrimination.

We also provided our children with as much verbal instruction, from us or from others, as we could afford, guided by their own interests. With Rousseau's philosophy of learning by experience we also implemented many activities that can be traced to ideas from John Dewey including learning by doing, project-based learning, group activities, and providing materials related to the child's interests (Spring, 2008). Instead of schools, we sought out children's museums, science centers, zoos, and other public spaces where we could engage in this type of hands-on learning, as well as providing hands-on learning materials at home. Spring (2008) critiques those who took up Dewey's pragmatic ideas about education, but left out Dewey's ideas about "social imagination and the historical roots of occupations" (p. 284). Spring (2008) notes a disconnect in schools using Dewey's ideas in ways that led to conformity rather than interdependent thought, and group consensus over free individual action. I believe we did and still do a good job of enacting Dewey's philosophies.

While we disrupt the idea to understand the role of the worker in society as one serving the industrial aims, we do have important conversations about how what our children are learning fits into the greater social context of an interdependent society. For

example, as Liam began to explore divergent forms of music outside of old-time music, such as progressive bluegrass, we talked about the origins of old-time and why the Junior Appalachian Musicians (JAM) program teaches old-time music. The program began two decades ago with an emphasis on teaching old-time mountain music to a new generation before the elders who learned much of the tradition by ear and verbal instruction all died off. Though Liam was exploring new types of music, after considering the importance of preserving the history of this oral tradition, he began teaching in the JAM program in order to do his part to keep the tradition alive. He still teaches there today, taking his place in society passing the oral traditions on to an even younger generation of musicians. Yet, Liam still explored new musical genres and continues to do so. In addition, Liam regularly performs at nursing homes.

In part, because at home we've discussed the interdependent social imagination of Dewey, though not in those exact terms, as a way to find our place in an interdependent world. Liam's choice of music as a future profession is one that also involves a tension between isolation and interdependence. In one way, the musician is the lone artist seeking refuge from society to write. Certainly Liam does this as he often spends much time alone writing and recording music. However, we've had lots of conversations about the interdependent nature of what he wants to do. That as a musician his role in society is one not only to provide music as his way of working together in an interdependent world, but his role is to perform it live, interact with the public, and teach it to the next generation.

In addition, mentors like Si Kahn and Cathy Fink have worked with Liam to help him understand his role as a songwriter to tackle social justice issues in lyrics and music

— that a musician has a social responsibility to society to hold up a mirror through one's art and demand change for a more socially just world.

Hopeful Inquiry

This autoethnographic research about one family's deschooling/homeschool/unschooling experience, in particular within the context of a family with a child who experiences disability, helps fill a void of homeschool and unschooling narratives thereby opening the possibility of discovery of and choice in these or similar options for those who might seek an educational alternative to compulsory public, or private schooling. For those who say they simply *can't picture how it would work*, this autoethnography about unschooling provides one account of one family's experiences, which could open a path not for a duplication of this experience, but perhaps an inspiration to other families to forge ahead on their own unschooled journeys. The narrative provides not only inspiration, but also pragmatic ideas for other families to enact their own unique unschooling journey with, I hope, a transformative effect toward a just education.

Though much of the story focuses on tension and strife, I hope enough joy comes through the reading of the unschooling experience, so that the experience can be better known and understood, not only by others who might seek to create a similar experience in their own journey, but by medical, educational, and service practitioners, and policy makers. This knowledge could be a theoretical tool used to teach pre-service teachers to understand the diverse perspectives of families with children who experience disability, educate administrators who guide/create policy within schools to become more open and

willing to work with families, and policy makers at state and national levels who might shape policy affecting not only homeschoolers, but those who experience disability. Most importantly to me, is reaching other families who might realize that there are alternatives to the dominant ideology that public or private schooling are the only choices.

In addition, by publishing this account of unschooling, perhaps other unschoolers, and in particular those families unschooling children who experience disability, will share their own stories countering the fear many unschoolers feel (Rolstad & Kesson, 2013) by publicly presenting their own narratives creating more and more first-hand accounts of the homeschooling experience and in particular the unschooling experience.

This autoethnography forms a counter-narrative to popular media stories constructing homeschooling families as socially awkward and reclusive, religious fanatics (Hauseman, 2011). By putting this story in public, I counter flat characterizations in news media that fuel fears of rejection, regulation, and intervention in homeschool and unschooled families, and in doing so it is my hope to alleviate the reluctance to share educational practices outside of tightly knit social circles of like-minded families. In doing so, I emphasize that this is one version of homeschooling, and in particular unschooling, not an exemplar or blueprint, but just one story that hopefully will inspire others to create their own unique homeschool and unschooling stories. If all research is fundamentally about human beings, thus a relational act as Freire (2000) describes of "hopeful inquiry human beings pursue in the world, with the world, and with each other" (p. 72), then my research is a *hopeful inquiry* moving toward a transformation of the world. This research is moving toward social justice not in a way that says this is *what is*,

but instead in the critical notion of what *could be* or even the political notion of what *should be*.

Autoethnographic Storytelling

Autoethnography becomes a powerful tool for telling these stories and for doing what Howard (2005) calls *counterstorytelling* to "offer narratives which can counter much of the rhetorical accounts of their identities that frequently describe them as culturally and socially deficient, uneducated, unmotivated, prone to violence, and anti-intellectual" (p. 975). While Howard writes about African American males, I find his theories often cross over to apply also to those who experience disability. We need *counterstories* in the disability narrative. And autoethnography becomes a tool to produce those stories.

Ellis (2004) describes the call to autoethnography as she says Buddy Goodall described the call to ethnography, "you don't really choose ethnography, it chooses you" (p. 26). I certainly feel that call and a commitment to writing more autoethnographic stories. Witkin (2014) points to the important role of autoethnography today:

> Autoethnographies such as these…not only describe what was an is, they pull us into what happened and what is happening, here and now, and they make us authors of the future, whatever it confronts us with…the power of the autoethnography lies in its ability to deepen the author's understanding and respect for the self in context while doing the same for the other…considering these narratives encourages us (i.e. gives us courage) to appreciate other people's unending life stories more fully. And by doing this we hope to e able to support others in shaping their own lives. (pp. ix-x)

That is the agency I hope others can find to enact in their own lives, especially those experiencing disability. But there is work ahead other than writing more autoethnography.

Future Social Justice Work

The past 10 years of working on my research has also been a time of retreat from *boots on the ground* social justice work. My experience in public schools left me with bitter taste in my mouth and a reluctance to even drive by my local public school, a place I often spent time volunteering, talking, advocating on the ground on an almost daily basis before we unschooled. Our journey forced to focus inward and on figuring out what our homeschooling journey would look like outside of public schools and we have not returned. As that journey unfolded, medical issues with multiple run-ins with cancer forced us to focus on family, health, death, and healing. Medical issues with Kenyon perhaps refocused our lives inwards more than anything.

But now 10 years after my journey began, as death has claimed my mother and so many uncles, as Janet heals from breast cancer, as Liam prepares to leave home to continue his own journey in college, as I finish my graduate work, I can see a precious time entering back into the picture. Time I could use for social justice work. Time to return to work on boards for nonprofits, volunteering in schools, or helping folks navigate the Medicaid system. I've learned so much in struggling against the system that perhaps that knowledge could now be employed in helping others navigate the system. For

example, in our year-long struggle to get Medicaid to pay for an electric wheelchair for Kenyon, I now have a knowledge base to help others through that complicated and convoluted and confrontational process.

Beyond serving as an advocate on state-wide, regional, or local boards, and working on the ground helping others with the day-to-day reality of navigating a complex medical-system, I hope teaching will be a site of future social justice work. Whether I continue to teach in communication studies or move to a department of education, I believe I will have the chance to create change through continuing my commitment to social justice through teaching at the college level. Already this work has reinvigorated my commitment to bring social justice lens into the communication classroom and autoethnographic methodology as well.

I have been approached several times during my dissertation process to get involved with a program at my university that brings a post-secondary college experience to students experiencing disability. During my graduate work I worked with a similar program called Beyond Academics at UNC-G. Already, at Appalachian State I've worked with three students from the program in my classes. I see myself getting more involved with the program in the future, or a similar program, if I change where I work.

In addition, I proposed and had approved a themed class for incoming first-year students at Appalachian State. The course, *Disability is Beautiful*, would involve release time from my department, and perhaps now is the time to push for that time to offer this course. I also see other avenues for publication outside of the academy, such as blogs,

vlogs, or web pages that might serve as spaces for connection, advocacy, networking, and connection for those in and outside of disability culture in order to advance the causes of social justice.

Above all my social justice efforts will center around Kenyon. Fighting alongside Kenyon for his own rights is perhaps a tough enough battle for anyone or any family. Even using the thick descriptions of autoethnography, I don't think folks living outside the experience of disability understand the time and energy and money it takes to support a person who needs a high level of daily assistance and personal care. There is often an assumption many folks make that life is somehow easier with disability. Folks who say *I bet you enjoy those disability checks every month*. No, we never have qualified for disability, so have never received a monthly check and even if we did somehow qualify that nearly $700 a month wouldn't even cover the cost of the insurance, copays, coinsurance, and deductibles we pay for Kenyon's care. They say *sure must be nice to stay at home and take care of Kenyon all day*, *huh*? Yes, it honestly is an honor and privilege and full of joys impossible to articulate until you've experienced it. But, I do want to push back on that particular narrative, of the experience of disability being one of leisure. And perhaps in my autoethnography I did not address enough the challenges of parenting and caring for someone with a high-need of care.

I realize that my first commitment above everything is the day-to-day, unrelenting, unstopping assistance that my family gives to Kenyon on a 24-hour basis from always having a person present in case of seizure to providing a complicated regimen of medications that must be administered in careful doses at precise times to a

set of daily exercises/stretches Kenyon needs help with to assistance each time he needs to go to the bathroom, assistance dressing, assistance eating, assistance moving from one space to another to a seemingly unending calendar of doctor appointments often involving a 6-hour round trip to Duke in one day to an even more unending stream of paperwork to acquire basic medicines, medical equipment, and medical care that often results in crisis situation when Medicaid cancels insurance without notification leaving Kenyon without the daily meds he needs to survive…and the financing of it all, which is a significant cost to our family….plus all the normal labors of everyday life from dishes to yard work to taxes to washing cloths and cleaning…there isn't a lot of time left for changing the world or volunteering at the local school. It's not a life of leisure.

We do have the privilege of having two or even three, counting Liam for now, people in the home to help care for Kenyon. I imagine how this journey might be different as a single-parent, and it seems not just different, but quite impossible. With two of us we've arranged our lives so one person works in the day and the other at night so that there can always be one of us at home to care for Kenyon — we've also had the educational privilege to work in public schools and higher ed, where we do have more time around holidays and summers than a typical 260-day-a-year worker. That said, finding time for this research has been extremely difficult and I know that finding time for social justice work will be a difficult and time-consuming process to attend.

However, I do have the same time I used to write and research this dissertation — the wee hours of the night. After everyone is in bed, and all the day's chores are done, and all the bills are paid or at least put off for a month, after all Kenyon's care is done,

and all is quiet…I can sneak to my iMac and write…I think this where I can do my best advocacy…writing autoethnography and continuing to story our lives as spaces for simply just education, just living, always moving with hope toward a more socially-just world.

Unschooling is Just Education

I started this research by asking is unschooling just education? I believe it is, not just in Illich's (1971) idea of learning being an act of simply living, but also in regards to a socially just, and social justice-oriented education. I asked:

> *What is the story of one family's unschooling experience, in particular unschooling with a child who experiences disability?*

In the final evaluation and reflection on this research, the autoethnography of my deschooling/homeschooling/unschooling journey with my co-companions and co-conspirators in learning and living — the love of my life Janet, and the loves of my life Liam and Kenyon — I leave you with words written by one of my graduate school professors, Christopher N. Poulos (2014):

> If this story speaks to you, if it reaches your heart, if only just a little, then autoethnography has done its work. And its work is powerful, pivotal, transformative. Welcome to my bridge. The bridge of hope, of possibility. Maybe together, we can find our way…to the next story. (pp. 356-357)

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